

**THE RIGHT TO SUPPORT: SEVERELY DISABLED CHILDREN & THEIR
MOTHERS**

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ABSTRACT

The author examines how severely disabled children and their mothers, who are usually their primary caregivers, are treated by Canadian law and policy. She identifies and analyzes deficiencies in care and other supports the state makes available to them. She further provides an analysis of the role of the state as it increasingly privatizes responsibility for supports, including unpredictable and often complex forms of care, situating them in practice, with mothers. Caregiving mothers are required to provide what comprises maternally complex care, which may be medical, neurological or psychiatric in nature. Within complex care, visible and hidden costs have been off loaded onto caregiving mothers by government. Using conceptual frameworks from feminist standpoint theory and drawing on Paolo Freire's theory of critical consciousness, the author analyzes legal cases, legislation and policies, as being founded upon a series of powerful myths. She assesses the paradigms that underlie current legal arrangements, in particular, the roles assigned to mothers of children with severe disabilities. Her analysis engages with administrative, tort and constitutional law, and includes a focus on the steps taken by the province of Ontario to end the voluntary care provision to mothers with disabled children through its child welfare jurisdiction. She shows where such practice may not comply with legal requirements in each of the areas of law she examines, building an argument that Ontario may not refuse such care to mothers. Legal reforms and other approaches that could enable severely disabled children and their mothers to achieve more just outcomes are presented as a series of recommendations.

DEDICATION

For Susan Murphy and Beth Lesser, for all the sharing about care and caring over the many years, and for the Calgary woman, whoever you are, for calling 911 and remaining with my son until an ambulance arrived. I think of you three with immense gratitude.

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CHAPTER ONE: Introduction

The goal of this dissertation is to present a clear picture of what legal rights to support mothers with severely disabled children have in Canada; to present their situation within a framework that makes visible areas where rights for mothers and their severely disabled children are absent or weak; and to propose ways for mothers to have their rights conceived in a more just manner consistent with entitlements.

The legal rights to state support of mothers with severely disabled children have not been closely examined either by legal scholars or by practicing lawyers in Canada.¹ Some scholars have examined legal-oriented advocacy for disabled children in education domains, i.e. with respect to accessing special education and needed assistive devices.² These scholars discovered that it was primarily mothers who advanced rights for disabled children. Mothers themselves have examined legal issues affecting their care for their own disabled children in books and public talks, but these are few, and have garnered little public attention. In neither case is the issue framed in the context of the need to assert and protect *mothers'* legal rights to support in their role as caregivers to severely disabled children, who are themselves also rights' bearers.

In order to address this oversight, I pursue four research questions with a view to reframing discussions concerning mothers with severely disabled children. These four questions are as follows:

- (i) What are the legal rights of mothers of children with severe disabilities to state support in Canada? (ii) What should the legal rights of mothers of children with severe disabilities be? (iii) What are the legal

¹ Although some interviews have been given and articles published by them about issues that have arisen in their practices: see Interview of Doug Elliott by Karen Howlett in Karen Howlett, "Ontario Minister's Departure Leaves Disabled Kids in Limbo" *The Globe and Mail* (4 July 2005) A5. Elliott was one of the legal counsel in *A.L. 2 v Ontario (Ministry of Community and Social Services)* (2003) 65 OR (3d) 289, 41 RFL (5th) 123 (ONSC) [*Larcade* (2003) cited to OR] (The *Larcade* litigation began in 2003 with the *A.L. 2* motion for class certification, on appeal the style of cause was changed to *Larcade v Ontario*. [*Larcade v Ontario (Ministry of Community and Social Services)* (2006), 32 RFL (6th) 390, 2006 CanLII 17943 (ON SCDC)]. I will refer to all levels of decision in this matter as *Larcade*, though I specify which decision in the footnotes.); Gary Joseph, "Adult Child Support Distinction Raises Charter Issues" (2012) 32:26 *The Lawyers Weekly* 14, Joseph was the father's legal counsel in *Vivian v Courtney* 2012 ONSC 6585, [*Vivian* (2012)]; Estate lawyer Daniel Dochylo's book *Entitlement to Support of the Adult Disabled Child – From a Parent or Estate* (Toronto: Ontario Bar Association, Institute of Continuing Legal Education, 2009); Abby L. Griener, "Evidence Based Analysis of the Spousal Support Advisory Guidelines in Alberta" (Paper delivered at the Canadian Bar Association Alberta, Alberta Law Conference, 30-31 January 2014) online: Vogel Lawyers <<http://www.vogel-llp.ca/~ASSETS/DOCUMENT/PDF/2/A2D2-00093939.PDF>>.

² See Katherine Runswicke-Cole, *Parents as Advocates: The Experiences of Parents Who Register an Appeal with the Special Educational Needs and Disability Tribunal* (Doctoral Dissertation, The University of Sheffield, School of Education, 2007) [unpublished]; Denise Frankoff, *Exploring Legal Consciousness: Experiences of Families Seeking Funding for Assistive Technologies for Children with Disabilities* (Doctoral Dissertation, Northeastern University, Department of Law, Policy and Society, 2010) [unpublished].

rights of children with disabilities to state support? And (iv) how do the legal rights of the child with a disability fit with the legal rights of mothers to public support within existing frameworks?. These questions, as I detail more fully below, are best informed by caregiving mothers' own knowledge and experiences of attempting to provide care to their disabled children from within an inadequate system of state support. In answering these questions, and informed by the knowledge and experience of caregiving mothers, I propose what I consider to be a more just and caring alternative to the state supports currently available to mothers under primarily provincial, but also federal, law in Canada. .

Overview of My Arguments

I explore and analyze the role and conduct of the state as it increasingly privatizes care of severely disabled children, entrenching responsibility for complex disability care primarily with mothers. As I show, the shifting of supports available to mothers with disabled children by the state has had profound political, social and economic impacts on them.

Given the weak patchwork of systems of state supports available to mothers of disabled children, the 'trapping' of supports into limited and ineffectual spheres of allocation and adjudication, and the pervasiveness of a particular cultural understanding of caregiving mothers, it is often extremely difficult for mothers to access needed and appropriate levels of support. How difficult it is cannot be appreciated without examining the steps these mothers must take to try to access supports. Accordingly, in order to understand what is missing from existing supports to mothers, this research analyzes where gaps in available provincial supports lie through reference to the legal cases and other activism of caregiving mothers of severely disabled children.

By examining the activism³ of caregiving mothers in their attempts, through legal proceedings, to secure appropriate support for their severely disabled children, one can learn about the shortcomings of the current legal contexts of state care provision to disabled families. Further, one can identify and interrogate the gendered conceptual barriers of notions of motherhood that force caregiving mothers to relinquish care of their severely disabled children to the state. My research reveals that the claims of mothers with severely disabled children are confined in ways that prevent systemic remediation of their

³ I note here that in the context of disability, 'conscientization' as a framework has been undertaken elsewhere. For example, published after I defended my research proposal, is Beatriz Miranda-Galarza et al's "The Power of personal knowledge: reflecting on conscientization in lives of disabled people affected by leprosy in Cirebon, Indonesia." (2013) 9(2): Knowledge Management for Development J 85-104. These authors focus on critical consciousness of researchers, some of whom are disabled, researching with disabled people. They comment that "Understanding how personal knowledge is produced, appropriated and shared will facilitate a move from solely valuing personal knowledge as 'experience' to seeing it as an important component of emancipatory disability research, *ibid* at 89.

need of support, and that their efforts to obtain more support merely add to their hardships.⁴ This research suggests that in no area of law are mothers' claims to support routinely anticipated, included, facilitated or realized. An analysis of a controversial and legally contested Ontario policy is used (a) to contextualize the unsupportive practices and policies used by governments for caregiving mothers, and (b) point to manifestations of maternal awareness of disability support law's harshly gendered features, which are strikingly similar across Canada. Consequently, in taking steps to address their legal right to support, and in order to realize their rights to it, mothers with disabled children must be conceived and treated as a dyad, unique in law

There are deep contradictions between the way society represents caregiving mothers, and the harsh realities of the under-supported and unsupported complex or otherwise onerous forms of care demanded of them. Shifting long-held cultural understandings of the complex care required of mothers of the severely disabled child can do powerful ideological work in the legal and policy domains, presently fraught with tension and injustice in addressing the real needs of mothers with severely disabled children.

Legal Rights

Martha Minow defines 'rights' as legal rules that govern relationships between private individuals/groups and between private individuals/groups and the state. These rules or rights are presented in the shape of enforceable claims.⁵ In referring to legal rights in my thesis, I refer to the following. (i) Statutory entitlements, which are provisions in statutes that entitle mothers with severely disabled children to bring claims for support. (ii) The right of mothers with severely disabled children to apply for benefits where eligible. In my thesis I treat benefits as legal rights because other kinds of legal claims can be made in respect of them. In certain circumstances for instance, claims may be brought for judicial review of denial of a government benefit. (iii) Rights claims made where no 'caregiver-mother specific' legal right exists. Such claims encompass forms of support that exist already (like CPP), but have either not been extended to caregiving mothers, or are denied to them in their caregiving situations. Rights claims include novel claims to rights that caregiving mothers want to be able to exercise, such as having a court require government to extend certain rights to them. These rights may be asserted as constitutional law claims.

⁴ The word 'confined' is used with reference to the use of the word "enclave" by Nancy Fraser in her work. She refers to the enclaving of certain matters into specialized arenas where "they are shielded from general contestation". Once thus confined, these matters "entrench as authoritative" the interpretation of needs. Nancy Fraser, "Talking About Needs: Interpretive Contests as Political Conflicts in Welfare-State Societies" (1989) 99:2 *Ethics* 291 at 299 [Fraser, "Talking About Needs"]. Fraser also describes androcentric value patterns as structuring social interaction. She theorizes that these are legally codified in family (and other) law and inform legal constructs. Nancy Fraser, "Feminist Politics in the Age of Recognition: A Two-Dimensional Approach to Gender Justice" (2007) 1:1 *Studies in Social Justice* 23 at 26 [Fraser, "Feminist Politics"]. This explains the mother's status subordination, examples of which include the dismissal of the weight and expense of complex care in disputes with government or fathers, as well as the construction of care as an extension of woman's biological function of reproduction.

⁵ Martha Minow. "Interpreting Rights: An Essay For Robert Covert". (1987).96 *Yale Law Journal* 8, 1860, at 1866.

(iv) International human rights treaties and declarations. This refers to the obligations of government to consider the rights provided in provisions contained in international human right instruments, to which Canada is a signatory. (v) Human rights codes are included as rights. For instance “family status” is a ground of discrimination that may be claimed by mothers with severely disabled children. Finally, (vi) there are relational rights, which are not recognized in law, and so do not have force of law. However, the concept of relational rights is helpful in analyzing the dependency of severely disabled children on their mothers for extraordinary care. For example, relational rights scholarship elucidates the fact that *legal* rights cannot account for support of mothers with severely disabled children as long as they retain an individual focus. I argue it is the combination of the present conceptualization of rights as individual, rather than relational, along with the social and political positioning of caregiving mothers in neo-liberal and investment state politics of supporting those children presenting as comprising a good return on the state’s investment in them, that have led to the cobbling together of an inadequate and indeed dangerously unstable ‘system’ of supports.

The Contexts

This dissertation is informed by a broad range of scholarly disciplines and areas of law, therefore, it is important to discuss context. In sum, the contexts on which I particularly focus are the Canadian legal landscape, with privatization forming part of that context. Legal decisions concerning mothers with severely disabled children provides further context. Another context is child disability activism as it relates to mother’s pursuit of recognition and support. Other context addressed includes the conceptual frameworks of feminist standpoint theory and critical consciousness. I further include media coverage and analyses of situations that have arisen. I address the role of resistance and transformations of caregiving mothers, and finally I consider the context of social standing of caregiving mothers in Canada.

My involvement and interest in children with disabilities led me to question the fairness of their circumstances, which I realized in the 1990s, included their mothers’ provision of care. The flurry of litigation against the province of Ontario in the 1990s by mothers with disabled children, challenging state approaches to public supports⁶ brought my attention to the inadequacy of state-sponsored care to address the needs of mothers with disabled children. An analysis of this activity, activism and litigation against the provincial government forms the primary context of my dissertation. This research asks ‘what

⁶ According to Christopher P. Manfredi & Antonia Maioni, “Reversal of Fortune: Litigating Health Care Reform in *Auton v British Columbia*” (2005) 29 Sup Ct L Rev 112 at 134, who reference data from the Autism Society of Canada, “180 cases involving 1,600 families” of autistic children were still before the courts in Canada in 2004 while *Auton (Guardian ad litem of) v British Columbia (AG)*, 2004 SCC 78, [2004] 3 SCR 657 [*Auton* (2004)] was being heard. This is an avalanche of childhood disability litigation, yet this is a fact of which few, including many disability rights activists, are aware.

are the legal rights of mothers and severely disabled children to state support?’ and ‘what should they be?’ questions that I will address in my literature review and arguments.

Contextualizing Context

Context has been defined as “the circumstances that form the setting of an event, statement, or idea, and in terms of which it can be fully understood and assessed.”⁷ With respect to this research, important questions to ask regarding caregiver rights are ‘who frames the context under discussion?’ and ‘for what purposes?’⁸ My project is situated within different contexts. The first is the context I use to approach my research. For my purposes, the Canadian legal landscape forms the dominant context, since the issues I seek to address are those relating to the legal rights of caregiving mothers of severely disabled children in Ontario and elsewhere in Canada. The province of Ontario’s privatization of available provincial supports is a significant context that demonstrates institutional indifference to the seriousness and complexity of care needed by severely disabled children. Of course, law and policy are inherently embedded in the cultural, political, and socio-economic contexts in which they are created and shaped and so I consider these too.

Secondly, there is contextualized judicial decision making: a reading of the contexts in which the right to support of children with severe disabilities is concerned may involve narrow legal issues such as which court orders were enforced previously, when and why. Notably, some judges in *obiter dicta* and in decisions respecting the right to support have insisted that in deciding issues about social justice, contextual approaches to facts and law are essential. For example, in her dissent in the Supreme Court of Canada case *Gosselin v Quebec*, Madam Justice Louise Arbour expressed this view.⁹ Justice Arbour held that to exclude context from an evaluation of a claimant’s *Charter*¹⁰ rights results in unjust decisions.

Contextualized approaches taken by non-dissenting judges have likewise been supported by scholars examining gendered disability discrimination.¹¹ In *Eldridge v British Columbia (Attorney*

⁷ Oxford Dictionaries Online, *sub verbo* “context”, online:

<<http://www.oxforddictionaries.com/definition/english/context>>.

⁸ I suggest that the framing of context is something that ties into epistemological considerations, such as whose knowledge is under consideration, as raised by Lorraine Code, *What Can She Know? Feminist Theory and the Construction of Knowledge* (Ithaca, NY: Cornell University Press, 1991) [Code, *What Can She Know?*].

⁹ *Gosselin v Quebec (AG)*, 2002 SCC 84, [2002] 4 SCR 429 [*Gosselin*]. The court in *Doré v Barreau du Quebec*, 2012 SCC 12, [2012] 1 SCR 395 concerning the adjudication of the *Charter* right used the word ‘context’ 20 times in its decision [*Doré*].

¹⁰ *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982 (UK)*, 1982, c 11 [*Charter*].

¹¹ See e.g. Fiona Sampson “Beyond Compassion and Sympathy to Respect and Equality: Gendered Disability and Equality Rights Law” in Dianne Pothier & Richard Devlin, eds, *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver: UBC Press, 2005) 270. Disabled women may be discriminated against in ways disabled men and non-disabled women are not.

General),¹² a case where persons who are deaf alleged that not having been provided with interpreters impaired their ability to receive proper treatment and that this lack was discriminatory and breached their right to equality under s 15(1) of the *Charter*, the word ‘context’ appears 15 times. Drawing on the words of Justice Wilson in *R v Turpin*,¹³ the *Eldridge* court reiterated that the determination of whether a law is discriminatory requires a contextual examination, and one that must go beyond the legislation itself, to the social, political and legal context of appellants.¹⁴ This provides a legal context for disability rights. A broader reading of the context of a lawsuit would therefore consider the circumstances under which the claim for a right to support for children with disabilities is being advanced, or rejected.

Such circumstances may be social or they may be legal, but most often, they are both. *J.M.S. v F.J.M.* was an appeal from an order varying child support to the mother of a disabled child who was a charge of the state as a crown ward.¹⁵ The majority held that while the child welfare agency might seek support from the appellant father¹⁶, the mother of the child could not, because although she continued to care for and support the child, she no longer had (legal) charge of him. In her dissenting judgment, Madam Justice Anne M. Molloy opined that in determining the mother’s entitlement to support, it was relevant to consider the particular context in which the protection order arose, and that it involved a child with disabilities, wherein “the nature of those disabilities made it impossible for his mother to continue caring for him on her own. He required a residential placement, the cost of which was beyond his mother’s financial means.”¹⁷ Context, like this one, may be contested, depending who is framing the context and for what purpose.

A third context for my project is child disability activism outside of Canada, which has had an impact on activism within Canada. Caregiving mothers in diverse nations have been confronting the impacts of neo-liberal and post-neo-liberal ideals of at-home complex care for severely disabled children all over the world, and their challenges can helpfully inform Canadian research on disability rights. By studying international cases in the provision (or denial) of state-sponsored disability support, one can get a sense of the different ways that varying ideologies affect the availability of state support to marginalized families. Uncovering and considering these ideologies provides context for understanding the various barriers caregiving mothers of severely disabled children face. Interrogating the belief systems that inform legal policy is another significant context of my project. Context framed by mothers is typically in pursuit

¹² *Eldridge v British Columbia (AG)*, [1997] 3 SCR 624, 151 DLR (4th) 577 [*Eldridge* cited to SCR].

¹³ *R v Turpin*, [1989] 1 SCR 1296, 96 NR 115 [*Turpin* cited to SCR].

¹⁴ *Eldridge*, *supra* note 12 at para 55.

¹⁵ *J.M.S. v F.J.M.*, [2005] 79 OR (3d) 528 at para 46, 2005 CanLII 25769 (ON SCDC) [*J.M.S.*].

¹⁶ *Ibid* at para 33.

¹⁷ *Ibid*. In both *J.M.S* and *Gosselin*, dissenting judges emphasized the need for consideration of the particular context as essential for a just financial outcome.

of recognition and support. This context is tied to my conceptual frameworks of feminist standpoint and critical consciousness, discussed below.

Canadian media has reported on the plight of children with severe disabilities and their mothers.¹⁸ As well, Canadian media has reported on the childhood disability-related reports of provincial government-appointed watchdogs.¹⁹ Some media reports reflect outrage at the status quo for caregiving mothers and disabled children, while others reflect support for the state's version of acceptable care. Media interacts with (and reports on) the social, political and economic contexts informing legal policy, therefore analyzing media reports allows me to take a deeper look at how the issue is presented, debated and thought about publicly, and I analyze public attitudes made apparent by contemporary media reports in Chapter Four. Media, as will be seen, can assist with contextualizing need of support to caregiving mothers.

Resistance and transformation is a further context for my project. Thus my research includes mothers' voices in the context of political transformation and resistance.²⁰ My dissertation tracks how mothers with severely disabled children have come to resist "motherhood's gendered requirement of

¹⁸ See, for example, the series of articles by Tanya Talaga in the *Toronto Star*, as well as the series on difficulties with autism services that also ran in the *Star*. Shelley Page has reported on these issues in *The Ottawa Citizen*. Tanya Talaga, "Watchdog called his role 'bulwark of democracy': in Marin's First Report Since Attempted Ouster, Ombudsman Outlines Work Done in Past Year", *The Toronto Star* (16 June 2010) online: Ontario Ombudsman, <<http://www.ombudsman.on.ca/Newsroom/Ombudsman-in-the-News/2010/Watchdog-calls-his-role--bulwark-of-democracy--In.aspx>>; Tanya Talaga, "'Where's Ontario's Humanity?' Mom Asks", *The Toronto Star* (30 July 2009) online: The Star <http://www.thestar.com/news/ontario/2009/07/23/wheres_ontarios_humanity_mom_asks.html>; Tanya Talaga, "No One Should Be Forced to Give Up Their Child", *The Toronto Star* (20 July 2009) online: The Star, <http://www.thestar.com/news/ontario/2009/07/20/no_one_should_be_forced_to_give_up_their_child.html>; Shelley Page, "Whose Child Is This", *The Ottawa Citizen* (7 February 2009) online: Ottawacitizen.com <<http://www2.canada.com/ottawacitizen/news/observer/story.html?id=5daf3500-8df4-4342-ab39-32cd2e32e63f>> [Page, "Whose Child is this?"].

¹⁹ Examples are the work of The British Columbia Representative for Children and Youth, Mary Ellen Turpell-Lafond Examples include her offices' Reports: Representative of Children and Youth of British Columbia, *Update: System of Services for Children and Youth with Special Needs* (Victoria: Author, 2010) online: https://www.rcybc.ca/sites/default/files/documents/pdf/reports_publications/update_system_of_services_2010.pdf [BCRCY, *Update 2010*]; and Representative of Children and Youth of British Columbia, *Isolated and Invisible: When Children with Special Needs are Seen but not Seen* (Victoria: Author, 2011) online: https://www.rcybc.ca/sites/default/files/documents/pdf/reports_publications/isolated_and_invisible.pdf [BCRCY, *Isolated and Invisible*].

²⁰ Transformation is a framework that stands in opposition to the dominant 'coping' framework applied to the situations of 'failed' mothers. The coping framework is a myth promoted by many, including some gender-blind critical disability studies scholars. For instance, unnamed commentators on the Council for Canadians with Disabilities (CCD) website have openly criticized caregiving mothers who state they required respite. Alison Cocks and Jenny Morris have criticized the dominant characterization and use of respite care as segregationist, which suggests that mothers actively engage in segregation of their own children. Cocks suggests respite care may be seen as a tool used to prop up the ableist social order. One could just as easily argue that to refuse respite care does exactly the same thing to women. In fact, many mothers with medically fragile and/or technology dependent children, are segregated. See Alison Cocks, "Respite Care for Disabled Children: Micro and Macro Reflections" (2000) 15:3 *Disability & Society* 507, and Jenny Morris, *Accessing Human Rights: Disabled Children and the Children's Act* (Barkinside, UK: Barnardos, 1998).

female self-sacrifice,”²¹ in an effort to protect the care interests of themselves in context of the extraordinary care required by their children, doing so in a variety of ways. Canadian blogger, ‘Claire,’ writing in her fifties as a sole-support parent of two, provides an example of this. In her final blog entry, entitled “Moving on” Claire states,

Most of us are tired. But there are some words of advice that I think I can give. There is no question that we make mistakes along this road of caring for another. The biggest one, *I have come to realize*, is to imagine that it is somehow morally mandated that to become a martyr in the name of a severely disabled kid. ...remember, all the enrichment you believe your child deserves, you deserve too. As advice, I would say to any new parent that, all along this road, make sure you factor yourself into the equation: and of course I know that a world lacking in supports can make this near impossible.²²

This research argues that moments of insight offered by support-seeking mothers of severely disabled children should shape the context in which support policy is formed. As psychologist Phyllis Chesler strongly states, “In a mother-hating culture it is cowardly and shortsighted to plead the case for children’s rights while remaining silent about mothers’ rights.”²³ There is cultural ambivalence towards mothers and in the case of children with severe disabilities that ambivalence is pronounced. As well, the disparate perspectives apparent in majority court decisions and dissents in the case law concerning mothers who are asserting their right to support reveal differences in judicial understandings of both caregiving mothers’ needs and their rights, as well as of the obligations of the state towards them. However, in order to better understand what mothers of the severely disabled need, one must have an understanding of their lived realities.

Atypical social standing is an important context. Caregiving mother’s socio-economic situations challenge any application of the blunt instrument of ‘class’ to them. Both highly educated, along with those much less educated, sole support mothers are often in no position to offer care to their severely child, unless they can find a partner willing and able to share in the care and expense. As a result severely disabled children with mothers from different ‘classes’ are made wards of the state. Consequently, many lone mothers in Canada from different socio-economic groups simply do not have an enforceable right to keep their severely disabled child, and those who try to retain custody often live with very modest or extremely low levels of support. Research conducted by The Canadian Roeher Institute *Finding a Way In:*

²¹ Alison Diduck, “Legislating Ideologies of Motherhood” (1993) 2 Social & Legal Studies 461. She refers to Marlee Kline and Susan Boyd as making this same assertion at 462.

²² Claire, “Moving on” (17 July 2014), *Life with a Severely Disabled Child: The Title Explains It All, Doesn’t It?* (blog), online: <<http://severedisabilitykid.blogspot.ca/>>. See Appendix A. (Italics not in the original).

²³ Phyllis Chesler, *Mothers on Trial: The Battle for Children and Custody* (Seattle: The Seal Press, 1986) at 356.

Parents on Social Assistance Caring for Children with Disabilities,²⁴ demonstrated that the presence of a disabled child lowered the ability of caregiving mothers to leave welfare.²⁵ There is other literature that points out barriers to needed levels of support where mothers are caring for disabled children. It is a problem that defies resolution under present neo-liberal policy approaches in many jurisdictions.

Canadian lawyer, Shelagh Day,²⁶ notes that few legal scholars have written about ‘defending’ the rights of mothers as opposed to ‘women’s rights’ more generally. Day comments that feminists ignored mother’s rights, believing such rights to be the realm of social conservatives. She states however that our job in defending the rights of women includes the rights of mothers.²⁷ She also comments that if we believe in women’s emancipation, we must defend the poorest single mothers.²⁸ Meanwhile social conservatives have not advanced the rights of less well-off single mothers to state supports. This category includes mothers with severely disabled children trying to survive in our weak welfare state. Thus the plight of caregiving mothers has not benefitted from the attention of feminist legal scholars they have needed. Moreover, there is a weakly developed children’s constitutional rights jurisprudence in Canada.²⁹ In light of these points, it should be no surprise that the support rights of mothers with disabled children are unclear and little-understood.

This dissertation attempts to bring mothers’ voices into the discussion about their rights together with those of their severely disabled children in order to recommend paradigm shifts in the way that care provision is conceived, legally enshrined and made available to mothers caring for severely disabled children.

An Outline of the Chapters

Beyond this introductory first chapter, in Chapter Two, I introduce my research pathway, which includes the frameworks I use to examine the legal right to support of mothers with severely disabled children, as

²⁴ L’Institut Roeher Institute, *Finding a Way In: Parents on Social Assistance Caring for Children with Disabilities* (North York, ON: Author, 2000) [Roeher, *Finding a Way In*].

²⁵ Peter Brandon and Denis Hogan’s research examined the relationship between both maternal disability and child disability on the ability of unmarried mothers to leave welfare. They found children with disabilities have the same effect on the ability of a woman to leave welfare as a mother’s own disabilities. Their research concludes that the presence of disability in mother and child “are essential to understanding why a mother may be unable to exit welfare in the face of a variety of welfare reforms designed to encourage work.” See Peter Brandon & Denis Hogan, “Impediments to Mothers Leaving Welfare: The Role of Maternal and Child Disability” (2004) 23:4 Population Research and Policy Review 419 at 431.

²⁶ Shelagh Day, “Mothering in Law: Defending mothers’ rights” (Paper delivered at National Association of Women in the Law Conference, Ottawa, Ontario, 11-12, 14 May 2007) (Ottawa: National Association of Women in the Law, 2007) online: NAWL <<http://www.nawl.ca/en/documents/2007NAWLconfProceedings.pdf>>.

²⁷ *Ibid* at 2

²⁸ Day note 26 at 11

²⁹ Nicholas Bala & Douglas J. Redfearn, “Family Law and the ‘Liberty Interest’ Section 7 of the Canadian Charter of Rights” (1983) 15 Ottawa L Rev, 274. I argue this is still the case. In this older article, they state that insights may be gained from analysis of American jurisprudence in this area, *ibid* at 275.

well as a discussion of the specific sources I use. I work primarily with two theories to inform my interpretation of the subject matter: feminist standpoint theory and the theory of critical consciousness.

The contextual factors I addressed above have varying roles to play. The contextual factor of the Canadian legal landscape undergirds every chapter. The contextual factor of ‘class’ is described as socio-economic features of caregiving and is a thread that weaves throughout chapters, as it is central to the need of support. Judicial decision-making as a context features largely in chapters 4, 6, and 7 where legal cases are examined with particular focus on decisions where context was considered and seen to matter. Finally, the context of mother’s resistance and transformation, like the legal and policy context, is focal. Particular attention is paid to legal claims and the submissions made in legal proceedings.

In Chapter Three, I move on to review selected relevant literatures, considering works from medicine, political science, economics, history, sociology, feminist and other legal theory, and Canadian public policy scholarship. The literature is necessarily diverse as my project cuts across numerous fields of inquiry and disciplines. Avoiding such a cross-disciplinary approach would result in gaps in an understanding of the complex legal situation in which mothers with disabled children find themselves. There is a focus on literature concerning legal rights of mothers with disabled children, as well as an examination of feminist and critical legal theories about state treatment of mothers.

In Chapter Four, I describe how care for severely disabled children has been represented in differently informed models of care, referred to as the charity model, the medical model, the social model, and finally, what I consider to be a more nuanced approach to thinking about care that I refer to as the combined model. Historically, these models of care have been at ideological odds and through elaborating and analyzing each, I critique the contested concept of ‘care burdens,’ (also referred to as burdens of care), that appear in different guises in these models. This critique is helpful in that it illustrates the history and complexity of thinking and theory in the area of disability and care. Classically, disabled people have been viewed as burdens to both their families and to the state, and this is an important matter I interrogate in the dissertation. I argue that a newer characterization of the burdens of care on mothers with severely disabled children will be important to considerations in advancing legal rights to support. Moreover, a mother’s process of problematizing the complexities of skilled care, including medical tasks, night work, expensive care and so on, represents a rejection of how such care is represented in major models of disability, as well as reflecting expressions of evolved critical consciousness of mothers under circumstances of oppression. The combined model, in countering and reframing mainstream critical disability and medical model characterizations of caregiving mothers, is an example of intellectual activism and, since it challenges two dominant ideologies concerning women and care, it is also an example of critically conscious feminist thought. This combined model, I later argue, has application to arguments concerning legal rights to support.

In a later section of Chapter Four under the subheading, “Going Judicial,” I address a celebrated Supreme Court of Canada disability rights case brought by a caregiving mother. It involves the issue of decisional capacity and the rights of caregiving mothers not to have to provide disability support and care across generations. I include this case in Chapter Four rather than in Chapter Seven, which examines private support, as I consider this case as key to an interrogation of societal burdens of care placed on women who have borne severely disabled children.

In Chapter Five, I provide a sketch of supports available to caregiving mothers of disabled children primarily in the province of Ontario, but with some attention to other jurisdictions. These include such things as stipends paid by the state to parents, homecare and enhanced respite, typical respite care, tax credits and deductions, and other related benefits. In doing so, I also provide a critical policy analysis, arguing that existing supports are inadequate and exist in weak administrative systems with low accountability to mothers. This section provides a foundation for the subsequent chapters in which caregiving mother’s legal activism is seen in legal cases brought by them for various forms of support.

In Chapter Six, I discuss Canadian legal cases where mothers have brought claims against the state concerning its denial of disability-related supports to their families. I use selected cases revealing diverse perspectives on such supports from the bench, to illustrate some of the challenges that caregiving mothers of severely disabled children face as they confront prevailing societal myths about childhood disability and themselves. Chapter Six exposes the chasm between how caregiving mothers understand their needs for support and how governments (informed by outdated but persistent cultural views of motherhood) view those needs differently. The chapter also exposes a series of prominent myths in the area of *public* law as it affects caregiving mothers. The rationale for doing so is to show that although supports may appear in statutes, and may be widely assumed to exist in the culture, it does not necessarily flow from this that such support will be realized by those in need of it. My analysis of these myths, along with mothers’ efforts to reveal the truth in the face of them, serves to illustrate how public law corrals mothers’ claims for support in the setting of childhood disability, rather than facilitating them. The overarching difficulty however, is that of mothers’ inability to hold the state accountable for their ongoing support, the very thing to which, I argue, they have a right. As well, the abandoning mother forms part of an ideology, one that undergirds motherhood in general, but which is more pernicious towards mothers in its ableist manifestations. Failed, bad, and non-coping mothers abandon; coping, successful, and good mothers do not. In comparison, the abandoning state does not receive such a harsh condemnation. Where caregiving mothers are concerned, their competence and value appear to be constructed through binary opposites, with (bad) abandoners as one construction and exemplary mothers as the other. Both are oppressive, with maternal deprivation and maternal exploitation taking place respectively.

In Chapter Seven, I unpack core cultural attitudes towards mothers, mothers' roles in caregiving, and attitudes towards the severely disabled that shape mothers' legal experiences in their efforts to secure appropriate care and financial support for their children through private avenues. I also examine the effect of their private litigation for support on public support responsibilities. Thus, I examine an estate case, and family law litigation, including a family law case that intersects with a (public law) child protection matter. In so doing aspects of their activism can be seen. I consider their acts of their bringing novel claims and in their speaking to the media about challenges to existing legal provisions in statutes dealing with their support and that of their disabled children. I also examine a tort case that has relevance to my thesis and which involves a mother advancing rights to support for care.

In Chapter Eight, I provide a conclusion to my dissertation, ending with a recommendation that seems to offer the most promise to require that the state support mothers and severely disabled children.

I now present my research pathway, which includes detailed information about my methodology. As will be appreciated, the pathway is a means to illustrate not only the right to support, but also the barriers experienced in realizing it.

CHAPTER TWO: The Research Pathway

The Scope and Limitations of My Research

The rights I consider are legal rights and include rights based in legislation, case law, and constitutional law. I also consider international human rights law in making my arguments that mothers with severely disabled children have legal rights to support. The types of supports that I consider therefore include those made available by government, including disability and income support provisions, family policy, provincial home care and enhanced respite, *inter alia* and child welfare systems. Family policy includes family law and legislation implemented by the state. My research ended April 30, 2017.³⁰ Given that the scope of my research is jurisdictionally specific, and given the challenges in defining disability, among other matters I note immediately below, there are limitations as to what I can examine.

This study does not include an inquiry into all mothers with disabled children in Canada who require and who are, arguably, entitled to support. First Nations on-reserve mothers and their disabled children are not included.³¹

A second limitation is the inability to define a scientifically or administratively or other agreed upon approach to categorizing children as ‘severely disabled’. Severely disabled children form a group with fuzzy boundaries.

Another limitation is that in Canada there is little information about these mothers and children. Some information about their needs appear in reported cases and government and Ombuds Reports. However census and other kinds of data related to support is incomplete. Information mothers provide to provincial governments when they are applying for support is not made public. Although it would be helpful to know how many applications have been filed in courts by mothers across Canada, there is no tracking of these cases federally or provincially. Moreover, applications for state support may be filed and abandoned, or judicially decided, but not reported. Some matters will have settled.

I would also like to have included information from parents’ affidavits in child welfare and family law proceedings from across the provinces since 1996 (a date chosen as it corresponds with the end of the Canada Assistance Plan and many of the shifts in policy pertaining to care took place after it ended). However, that would have required a different methodological approach than the one I proposed, as well as greater time and resources than were at my disposal.

³⁰ Any legal developments that occurred after that date are not addressed, although significant changes in law and policy after this date are noted where applicable.

³¹ The obligation to support this group of mothers and children falls under federal jurisdiction. There has been protracted litigation in the Canadian Human Rights Tribunal concerning First Nations status children with severe disabilities rights to support. One example of this is *First Nations Child and Family Caring Society of Canada and Assembly of First Nations v Attorney General of Canada (representing the Minister of Indian Affairs and Northern Development)*, 2011 CHRT 4. Although provincial child welfare jurisdiction governs as well, this area, while pressing, is beyond the scope of my research.

Childhood Disability Defined

Disability cannot be succinctly or neatly defined. For the purposes of my dissertation, I rely upon an impairment definition first, and later argue for a relational re-envisioning of severe disability in childhood. Children whose impairments fall within the purview of my project are those who have episodic or permanent chronic physical, *severe* developmental, behavioural, neurological or psychiatric conditions and who require an array of complex health and social services and supports that go far beyond that required by typical children or children with mild impairments. Important within this group are medically fragile and/or technology-dependent children with intensive health and social care requirements. This includes, but is not limited to, children who have a congenital or acquired multisystem diseases and severe neurological conditions. It includes those children with serious immune and - in some cases - nonspecific severe conditions.

This definition has been drawn from and expands upon that provided by Canadian pediatrician Eyal Cohen et al. who, while noting there is no uniform definition for children with medical complexity, also noted there were nevertheless family service needs for this group. Cohen et al. who provide a lengthy definition based on a broad range of impairments proposed that further research in the area might use a common description and evaluate needs, seeking such information from medically complex children, their families and health care system providers.³²

My description goes beyond Cohen's in that I include all children whose care is what I refer to as maternally complex.³³ Mine is not a medical or social model definition of disability, but rather a maternally-oriented definition, one that works with my research goals.

I am well aware that disability has been defined in the social model not as impairment, but rather as the result of constraints placed on people with impairments by society.³⁴ It is the social model of

³² Eyal Cohen et al, "Children with Medical Complexity: An Emerging Population for Clinical and Research Initiatives" (2011) 127:3 *Pediatrics*, 529 at 529. I choose a medical foundation for my definition to avoid the bias in Canadian disability rights advocacy for children, which I suggest favors responses to disability discrimination against those children with intellectual disabilities, over those children with serious medical disabilities. I also seek to go beyond needs of the healthy physically disabled child. Attending to the often-extreme needs associated with severe medical impairments in a child is central in the lives of a percentage of caregiving mothers. This issue has been overlooked outside of medicine.

³³ In 1999, The Roeher Institute used the title "Supporting Children with Complex Medical Needs and Their Families: Synthesis of Three Reports" for an important policy document. See Cameron Crawford, "New from the Roeher Institute" (ND) online: <<http://abilities.ca/new-from-the-roehher-institute/>>. Notably the Roeher Institute document referenced, at 15, C.G. Petr, B. Murdock & R. Chapin, "Home Care for Children Dependent on Medical Technology: The Family Perspective" (1995) 21:1 *Social Work in Health Care* 5, and therefore had medical disability as part of its focus. However, this paper was published in 2000 as "When Kids Belong: Supporting Children with Complex Needs – At Home and in the Community" (North York, ON: Author, 2000), without the word "medical" in it. The second title reflects a retreat from the word medical. Important scholars in the areas of women's health, like Olena Hankivsky, have referenced the latter document.

³⁴ Carol Thomas, "Sociologies of Disability and Illness" (New York, Palgrave Macmillan, 2007) at 57.

disability that informs the United Nations Convention on the Rights of Persons with Disabilities (CRPD).³⁵

However, since a large part of severely disabled children's 'environment' is provided to them by their mothers, who both legally advocate *and* care for them, the social model of disability on its own runs into difficulty in my project. In my view, mothers do not form part of a disabling milieu to children with severe impairments; on the contrary, they work hard to enable their children's optimal health status and inclusion.

Although even this point has been challenged by some in critical disability studies. Moreover, as I argue, mothers are themselves disabled, by virtue of their assigned roles as caregivers of severely disabled children. They have been socially disabled by (among others³⁶) the patriarchal arm of the disability rights movement, a feature I discuss in detail later.

As a result of these shortcomings, the social model definition of disability is not my primary definition. This does not mean that I subscribe to a "personal tragedy" childhood disability narrative such as has been attributed to the medical model of disability.³⁷ The medical model, with the modification of the description of complex care as maternally complex care in this project, serves the aims of a legal rights' analysis, which has to do with improving support for mothers who care for severely disabled children.

My Research Goals and Methodology

To reiterate, my aim is to portray the legal rights to support mothers with severely disabled children have in Canada; to present their situation within a framework that makes visible areas where rights for mothers and their severely disabled children are absent or weak; and to propose ways for mothers to have their rights conceived in a more just manner consistent with entitlements.

In examining the law concerning their support, I have chosen methods that fit within an overarching feminist legal methodology. Feminist legal methodology is noted to "encompass[es] multiple approaches, and methodologically broadly speaking it includes an analysis and critique of law as a patriarchal institution."³⁸ In her now classic article, *Feminist Legal Methods*, Elizabeth Bartlett advocates the use of legal methodologies in legal research that are grounded in women's experiences of exclusion, that rely upon feminist reasoning and that pay attention to the matter of consciousness-raising.³⁹ Bartlett's rationale is that such methods can uncover features of legal issues that mainstream

³⁵ *Convention on the Rights of Persons with Disabilities*, 30 March 2007, 2515 UNTS 3 [CRPD].

³⁶ State structures likewise do so.

³⁷ C Thomas, *supra* note ## at 57.

³⁸ Kristin Kalsem, *In Contempt: Nineteenth Ceneru Women, Law and Literature* (Columbus: Ohio State University Press, 2012) at 4, uses the phrase 'feminist jurisprudence' to describe a feminist legal method.

³⁹ Elizabeth J. Bartlett. "Feminist Legal Methods" (1990) 103 Harv L Rev 829

methodologies may suppress or fail to see. According to Bartlett, methodology matters because the methods selected by a researcher will influence suggestions made for legal reform.⁴⁰ Thus, while classically briefing the body of support law I have gathered would provide information about claims made, facts relied upon, evidence that was provided, what the decision was and what principle the ratio of the case articulated, such an approach on its own would be inadequate in answering my questions.

More than a classic brief-and-discussion is needed to ‘get at’ barriers standing in the way of the realization of support by caregiving mothers. Typical analyses fail, for example, to address sub-textual and contextual issues that are embedded in the text of legal cases. They cannot address attitudes, biases, assumptions, hidden litigation strategies, or other features that form part of disputes where caregiving mothers are concerned. As such, a typical analysis of a case may fail to elicit the impact of complex care on a woman’s economic survival or on her health, or her ability to continue to care for her disabled child in the absence of particular supports. Important *obiter dicta* and dissenting judgments that challenge the legal *status quo*, which are tied to structures that subordinate caregiving mothers, may also be overlooked. In order to do as Bartlett suggests, and use legal research that is grounded in women’s experiences of exclusion, I draw from the scholarship of A.W. Phinney III. Phinney’s research comprises a textual analysis of decisions, which keeps in mind the question of whether claimant’s rights to support are even seriously examined in the very law concerning their right to it.

Finally, I am mindful that “doing disability research” appropriately requires the use of research methods capable of addressing the unique aspects of disability oppression, and thus, a critical approach to legal analysis that is sensitive to issues of disability should prevail. Further, in keeping with the view held by some advocates that disability research should only be undertaken by disabled people themselves,⁴¹ my experiences of disability are set out in the section on my standpoint. Thus the requirement that “nothing about us, without us” advanced from within disability rights is fully met in my project, and from all possible angles.

Sources Relied Upon

In light of my research questions, the method I adopted to answer them involves a lengthy literature review. It also includes: an examination of relevant statutes, consideration of legal decisions involving mothers with disabled children, and reference to bar association publications. It includes non-governmental and governmental policy documents and the broader grey literature, which is notably very important in disability research, as well as to applicable international law. Below, I summarize the means

⁴⁰ *Ibid* at 830

⁴¹ See e.g. Colin Barnes & Geoff Mercer, *Doing Disability Research* (Leeds: The Disability Press, 1997) online <<http://disability-studies.leeds.ac.uk/publications/doing-disability-research/>>.

I used to access the literature, subsequently, I move on to discuss aspects of methods related to my particular use of legal cases sourced.

Academic Literature

To inform my research, law, policy, medical and social science and humanities journal articles were reviewed. Databases consulted included: Ethos; Osgoode Law Library Journals Portal and LexisNexis Quicklaw Commentary and Journals. York University eResources; Medline; Pubmed; CINAHL and ERIC were used. To keep the review current, literature was updated through searches in Google Scholar, including Google Scholar UK. Some items were accessed through universities other than the York University libraries, such as the Bora Laskin Law Library at the University of Toronto. I also requested individuals at other universities to track down articles and I used Racer Dam for an international interlibrary loan.

Grey Literature - Reports and Papers and Media

Much of the grey literature referred to, such as policy documents and non-governmental reports, was accessed either online or personally, from disability rights advocates. I used ProQuest to access older newspaper and other reports. I also relied upon the Dissertations & Theses @York database through York University. Trade newspapers were consulted. I examined Canadian federal and provincial government reports, websites, policy briefs and white papers, reports on government strategies; Fatality Inquiries; Ombudsman Reports; reports and books published by policy institutes;⁴² joint provincial government and policy institute reports; Senate Reports; American joint state and university reports;⁴³ case comments; conference papers;⁴⁴ blogs; podcasts: newspaper and online news reports and radio interviews.⁴⁵ Some grey literature I refer to was recommended to me by disability advocates. I looked for blogs and radio

⁴² The Caledon Institute of Social Policy, The Roeher Institute, Society for Children and Youth British Columbia among others. See e.g. L'Institute Roeher Institute, *As if Children Matter: Perspectives on Children's Rights and Disability* (North York, ON: Author, 1995) [Roeher, *As if Children Matter*].

⁴³ I obtained an American publication by George Thomas, *Is Statewide Deinstitutionalization of Children's Services a Forward or Backward Social Movement?* (Urbana-Champaign, Ill: University of Illinois School of Social Work in cooperation with the Illinois department of Children and Family Services, 1975).

⁴⁴ For example, those of Anna K. Kingston, "Maternal Power Against The Deaf Irish State: Unearthing the Narratives of Mothers of Children with Learning Disabilities" (lecture delivered at Gender and Power in the New Europe, 5th European Feminist Conference at the Lund University, Sweden, 20-24 August 2003) online: <http://www.atria.nl/epublications/2003/gender_and_power/5thfeminist/paper_319.pdf> and Mr. Justice Jacques Chamberlain, "The Application of the Rights of the Child by Canadian Courts since Baker: Coasting or Speeding Up?" (Paper delivered at the Conference "Making Children's Rights Work: National and International Perspectives," 19 November 2004), (Montreal: International Bureau for Children's Rights, 2004), in the area of legal rights.

⁴⁵ This includes reports of radio interviews, where the spoken words were transcribed, such as CCD reporting on a CBC radio interview respecting the death of six-year-old Charles Blais in Québec in 1996 as well as radio interviews from Great Britain. See eg, Interview of Jane Raca by Nick Ferrari [nd] on LBC Digital Radio, online: Yourlisten <<http://yourlisten.com/Danno/jane-raca-on-lbc>>.

interviews by caregiving mothers that reflected in my view a changed consciousness. I looked for newspaper articles that reflected dissonance between what mothers reported versus what the state held out through its spokespersons. I also looked for media reports on disability litigation. I also had in my possession a collection of still-relevant policy documents referred to in my M.A. research, which examined Canadian pediatric homecare in the context of human rights. That project involved communication with government offices, such as the Office des personnes handicapées du Québec.

Statutes

I examined statutes and their regulations from different jurisdictions as they arose in the cases and policy gaps I discuss. Thus, the examination of legislation was by no means exhaustive.⁴⁶ It would not have been possible for me to examine every statute that touched upon the support of caregiving mothers. However, I did not list this as a limitation to the research, since this approach yielded significant amounts of information about a great deal of the law with which caregiving mothers interact.

International Law

International human rights instruments and websites about them were examined, along with secondary sources about their relevance and application.

Legal Cases

Since I sought to survey the legal landscape of supports offered to mothers with disabled children, I examined cases from across jurisdictions. At the very least, I looked at every case my search terms produced. Many cases were similar to one another within support domains, and I refer to some of these, but I also selected cases that had something additional to say, for example, revelations in submissions or *obiter dicta*, or useful or interesting comments in reasons given by judges. I also looked for cases that were further litigated in a higher court, as I was interested in the characteristics of these disputes. Thus, I refer to matters heard in provincial, territorial and federal courts and tribunals. Child welfare cases discussed include those from Alberta, Ontario, and Saskatchewan.

Family law cases include those from Newfoundland and Labrador, Manitoba, the Yukon, Nova Scotia, British Columbia, Alberta and Ontario. Cases comprised of actions brought by fathers and mothers, and, adult disabled ‘children’.

⁴⁶ Peter et al commented that for their one article on just homecare for children in Canada, they came across 585 documents, which included a large number of statutes, guidelines and related documents. Elizabeth Peter et al, “Neither Seen nor Heard: Children and Homecare Policy in Canada” (2007) 64 Social Science & Medicine 1624 at 1626 on Table 1.

I also examined replies to applications to vary child or spousal support and appeals of those matters. A celebrated disability rights case from Prince Edward Island is examined in detail.

Cases for supports brought against government include those from Nunavut, Nova Scotia, British Columbia and Ontario. Discussions of the Blais matter in Quebec provided information about challenges with supports to sole-support mothers in that province.⁴⁷

In terms of legal jurisdiction, in addition to drawing cases from provincial and territorial support domains, I refer to federal cases brought in the areas of disability pensions, taxation, immigration and employment insurance. Thus, cases were drawn from across Canadian jurisdictions in diverse matters. However, given the number of provinces and territories to consider and the added federal disputes, since mine is neither a statistical nor a quantitative research study, I selected Ontario as a focus in Chapter Five.

Generation of Cases and Rationales for Choice

I searched for cases primarily in two well-known Canadian databases, CanLII (The Canadian Legal Information Institute) and NexisLexis Quicklaw. In total, using all methods to generate cases, I gathered and read approximately 184 decisions. I referred to the Westlaw database only to locate cases referred to elsewhere, but that I could not find in NexisLexis Quicklaw or CANLII. CanLII, the primary database, is a reputable database set up by and funded by the Canadian Federation of Law Societies. It has several search functions with which to access Canadian cases dating back to at least 2000, which covers the timeframe I am most interested in.⁴⁸ CANLII describes its reporting of decisions as ‘comprehensive’.

Thus, I chose cases primarily from a comprehensive bilingual and reputable Canadian collection. Moreover, CanLII is user-friendly, widely accessible, and free of charge.⁴⁹

I chose to present for analysis cases that narrate common experiences of support-seeking activities of caregiving mothers. Cases I selected demonstrate in the text of their decisions that among the difficulties mothers encounter in support law are pervasive and tightly held cultural understandings about mothers in relation to disabled children. Although mine is neither participatory nor empirical research, in referring to cases found in CanLII, lay people, in particular self-representing mothers and non-legal scholars, can access decisions to which I refer. Moreover, the feature of accessible cases I rely upon in most of my arguments allows for a form of replication and substantiation of my legal arguments by interested others from any discipline. The overall accessibility of cases used was an important consideration in their selection for analysis.

⁴⁷ I was unable to find the legal decision, however, and I rely upon media reports of it.

⁴⁸ In addition, this information appearing on the CanLII website, I also asked a law librarian Emerita at Osgoode Hall Law Library, Marianne Rogers, about the status of CanLII as a research tool. She advised me it was reputable.

⁴⁹ Only one case was accessed through Westlaw. It was one I could not find in the two mainstream Canadian databases I relied on. Neither NexisLexis Quicklaw nor WestLaw are accessible to non-students and non-lawyers as it is not free nor particularly user friendly.

Search Terms Used to Find Cases and Other Means to Access Cases

Search terms I used in looking for cases relevant to my dissertation were: disabled; disability; complex care; disabled child; adult disabled child; mother; child of the marriage; father; income, work; employment; support; care; protection; child support; homecare; respite; pension; enhanced respite; cost; access; health; custody, assistance; charge and government. These terms allowed me to access cases decided in the private law and public law litigation.

Within cases, I also used a variation of the snowball approach used in qualitative research, by following up on cases or academic articles judges refer to in their decisions and cases that parties used to support their claims. This was done to ensure my arguments either made reference to or kept in view, the body of cases to which judges may refer. In my view, this also added rigour to my approach, because as a group, such cases function as a beacon in what could otherwise be seen as an endless sea of cases.

In addition to searching in digital databases, I visited the Great Law Library (of the Law Society of Upper Canada) and systematically looked through the stacks of older Family Law Reporters for earlier-than CanLII's reporting decisions involving adult children with disabilities.⁵⁰ I also reviewed the *Ontario Reports* provided to me as a Barrister and Solicitor by the Law Society of Upper Canada each month. However, notably, during the tenure of my research, I did not come across a case examining support of mothers with severely disabled children.

Information about cases, and some court documents, were provided to me by lawyers at ARCH Disability Law Centre, Income Security Advisory Centre (ISAC), and the Ontario Administrative Justice Network (OAJN). Where Bar Association publications that I accessed mention certain cases as being important to the issues I examine, I refer to them. Where an author whose work was central to my project, referred to a legal case or law in a book as relevant, I accessed it.

One important public law case I came across appeared in the form of a published factum⁵¹ prepared by children's lawyer Jeffrey Wilson at his and Alexandra Seaton's Toronto Family and Children's law office waiting room in 2014.⁵² However, while I used cases harvested from diverse sources, as noted, I relied primarily on CanLII and secondarily on NexisLexis Quicklaw to help me answer my research questions.

⁵⁰ *Rakus v Rakus*, [1989] OJ Mo 1331 (QL) (ONSC) [*Rakus*]. Initially it did not appear on the Quicklaw search.

⁵¹ It was a loose-leaf insert from a family law reporter sitting alone on a glass coffee table.

⁵² It was a factum for two mothers suing the City of Toronto. One of them had a disabled child. "Monograph – Factum #001: *A.B. v City of Toronto*", (2009) 23:2 Ontario Family L Reporter, referring to *A.B. v City of Toronto* (2009), Toronto, CV -09-383263 (ONSC) [*A.B.*]. Notably, this case seems not to be recorded anywhere. Osgoode Hall Law Librarian Daniel Perlin believes the case settled.

Case Selection and Analysis Employed in Chapters Six and Seven

My research into the areas of public and secondarily, private support cases, as noted, was not designed as an empirical study. I did not create a document to track every single case I came across, nor did I create a matrix to record data from cases I do and do not refer to. In clarifying this point, my dissertation was not designed as research that relied on, for example, either coding, or statistical analyses. Nor was it a comparative legal analysis designed to compare decisions in one jurisdiction against those in another. I did not select decisions that reflected only one approach or orientation to support.

Instead, I selected a wide variety of cases, choosing cases that were: both older and more recent; that represented middle-class, upper middle-class, working-class and non-income earning mothers with severely disabled children; that were from different jurisdictions; that dealt with a variety of forms of support and with children with different kinds of disabilities. I selected cases where on occasion: one or other parent also had a disability; where judges appeared more and less sympathetic to the support claims being made. I looked for tribunal and arbitration decisions, motions, trial and appellate-level decisions in the provincial lower and superior courts and in federal courts.

I looked for cases in all areas of the law where disability-related support to caregiving mothers was dealt with. Thus, I examined at least one case in each of the following areas: labour law; employment law; disability pension regulations; criminal law; and income tax provisions.

In some instances, I only came across one case in an area of law dealing with support to caregiving mothers. The cases of Cyndy Moore and Cynthia Harris appear to be unique, for example, but important in spite of that. I looked in the area of child welfare law, social benefits law, including disability income support provisions. I examined a case in estate law, several in tort and in family law. Some of these cases did not strictly fall within one area of law, rather there was *overlapping*, which is a feature of disability support.

In my analysis of cases in Chapters Six and Seven, I drew from the techniques described in Phinney III's article, *Feminism, Epistemology and the Rhetoric of Law: Reading Bowen v Gilliard*.⁵³ Here I set out Phinney III's ideas and his use of them in his approach to the United States Supreme Court decision in *Gilliard v Bowen*.⁵⁴ Phinney III suggests that legal decisions may be read as text and as representing a challenge not only to the law, but also to ideology.⁵⁵ He observes that even though certain issues before the courts have impacted poor women's lives, the legal issues appear not to be about their legal rights. He argues that this has rendered certain mothers' rights invisible, in the very cases that are

⁵³ A.W. Phinney III "Feminism, Epistemology and the Rhetoric of Law: Reading *Bowen v Gilliard*" (1989) 12 Harv Women's LJ 151.

⁵⁴ *Bowen v Gilliard* 483 U.S. 587 (1987) [*Bowen*].

⁵⁵ Phinney, *supra* note 53 at 152, for example.

about their right to support.⁵⁶ To illustrate this, Phinney III uses the example of the infamous American Supreme Court case, *Gilliard v Bowen*, which involved a legal challenge to an amendment of a provision in a federal social welfare law, *Aid to Families of Dependent Children Act (AFDC)*. Before 1975 American families applying for *AFDC* were allowed to exclude from their entitlement calculation child support or a child's work earnings. This meant an entire family in need of support would not be disqualified from receiving benefits because a separated parent paid child support. After 1975 the *AFDC* Program was amended to require the right to receive child support be assigned to the state. The later 1984 *Deficit Reduction Act* required that families receiving *AFDC* declare child support paid to families living together and children had to give up all of their child support except the first \$50.⁵⁷ The amendment therefore resulted in the clawback by the state of child support payments made to single mothers in receipt of *AFDC*. In *Gilliard*, as Phinney notes, the court relayed that the standard of review was whether Congress had a rational basis⁵⁸ for its decision and the United States Supreme Court decided that it did.⁵⁹ However, Phinney points out that "in the end the court can maintain rationality as a justification for the child's loss only through considerable sleight of hand."⁶⁰

The history of *Gilliard* is best summarized in the decision on appeal to the United States Supreme Court, which upheld the legislation as not violating the constitutional rights of the plaintiffs. It sets out the history of the matter and I have reproduced that in Appendix B. Phinney III's claim is that the *Gilliard* decision served to create *further* hardships for poor mothers who were dependent on the state for support by upholding the practice of state clawbacks of child support. He states that the decision, *read as a text*... "suggests the ways in which rhetoric and ideology can interlock to produce applications of law that discriminate against women and the economically disadvantaged."⁶¹ He states that his focus in analyzing the case is "less on traditional legal analysis than on the nature and effects of the rhetoric at work in both the majority decision authored by Justice Stevens and the dissent written by Justice Brennan, trying to show how the literary qualities of these opinions both reflect and condition their antithetical conclusions."⁶²

⁵⁶ *Ibid* at 173

⁵⁷ Phinney *supra* note 53 at 151

⁵⁸ The brings to mind Lucinda M. Finley's comments in "Breaking Women's Silence in Law: The Dilemma of the Gendered Nature of Legal Reasoning" (1989) 64 Notre Dame L Rev 886. Finley comments on the patriarchal language used in law. In *Bowen*, *supra* note ##, the legally necessary "rational basis" for government action in a welfare matter led to child loss for an involved father and father loss for an economically vulnerable child.

⁵⁹ Phinney, *supra* note 53 at 171

⁶⁰ *Ibid*.

⁶¹ *Ibid* at 152

⁶² *Ibid*.

The use of the word ‘rhetoric’ by Phinney III may be analogized to my use of the word ‘myth’, which likewise draws attention to what is taking place in support cases that may not be apparent on the surface, but which are influential regardless.

It became apparent that I had reached what a qualitative researcher would call saturation, after approximately a year of gathering and reading the cases I had amassed. At this point, I began to note the same or similar kinds of arguments and submissions repeated, which, I argue below, reflects the persistence of particularly entrenched and powerful myths that get deployed in all areas of support law pertaining to caregiving of disabled children by their mothers. As my literature review reveals, caregiving mothers and their severely disabled children are socially situated in ways contested by these mothers. I was interested in accessing cases that provided typical examples of how public and private law both adequately and inadequately account for the support needs of mothers, and how legislation and decisions act to ‘tame’ their claims to support, even at times where mothers prevail. Rosemary Coombe, a Canadian scholar in critical cultural legal studies, posits that instead of emphasizing statutes or decisions in one’s legal research, one might instead pay attention to “the textuality and legal life of cultural forms as it is expressed in the specific practices of socially situated subjects”.⁶³ In reading such cases, I attended closely to: *obiter dicta* and dissenting judgments that had something different to say about maternally complex care and the support of it; the text and the subtext of submissions to the court, as well of course to the nature of allegations made by and about parties to the case. Phinney’s analysis showed me how support law can *create* conflicts between the rights to support of a child versus his or her mother. Coomb’s writing suggested that the law’s impact is often felt where it is least evident, in particular where people are misrecognized or unacknowledged in law’s legitimation. What law does not say it does or omits to do can be as impacting as what it does do and the question of for whom conflicts are made or who are silenced in law is worthy of note as it has application in my project. I kept my eye open for these legal dynamics in reading legal cases.

I do address situations where courts (including dissenting judgments) have gone beyond the usual understanding of statutory or regulatory provisions, and I address what happened there. This was important in discussions of problems mothers experience in seeking support in amounts greater than that which is typically available under present schemes or whose claims do not fit neatly into statutory requirements. Although there are limitations in what courts can do jurisdictionally with regard to awards of support, there are not the same kinds of limitations on what courts can *say* about support law. Thus, I include important *obiter dicta* seen in the discussions of cases I examined.

⁶³ Rosemary J. Coombe, “New Direction: Critical Cultural Legal Studies” (1998) 10 Yale JL & Human 463 at 478.

The Interpretive Frameworks Employed

I employ two conceptual frameworks in this dissertation; that of feminist standpoint theory, and that of Freire's concept of critical consciousness. Standpoint theory has been stated to work well in tandem with the theory of critical consciousness, with the exercise of one's standpoint having been stated to be a key element in developing critical consciousness."⁶⁴ It has been clarified that, "standpoint theory is more about the creation of groups' consciousness than about shifts in consciousness of individuals."⁶⁵ My project considers both individual and group standpoint perspectives.

Standpoint Theory

Standpoint theory is a feminist critical theory concerned with practices of power and the production of knowledge.⁶⁶ It is also a methodology. The theory claims that obtaining a standpoint offers critical insights.⁶⁷ I acknowledge at the outset that as a theory, standpoint has been controversial; with theorist Sandra Harding noting that it has been critiqued with both 'vigour' and 'overt emotional investment'.⁶⁸ This suggests that it proposes something threatening. Exploring why such reactions occur, Harding suggests reasons include standpoint theory's engagement with the "anxieties of our era" and in particular, identity politics. She adds that standpoint theory has been seen as contentious to both non-feminist and feminists alike. She counters these criticisms of standpoint theory with the reminder that the underlying rationale of standpoint applies importantly to feminism, in that women have long been "the object of others' knowledge projects", noting that previously, research areas and social policy that bear on women disallowed conceptual frameworks in which women were authors of such knowledge.⁶⁹ This, she notes, "ensured systematic ignorance and error, not only about women's lives but also about men's lives, in all their diversity, and about how any particular society's gender relations worked."⁷⁰

Standpoint theory has been persuasively defended by many other feminist theorists as well, which is why I employ it.⁷¹ Addressing its detractors, Nancy Hartstock asserts, "standpoint is not simply an

⁶⁴ Zulema Suarez, Peter Newman & Beth Glover Reed, "Critical Consciousness and Cross-Cultural/Intersectional Social Work Practice: A Case Analysis" (2008) 89:3 *Families in Society: J Contemporary Social Services* 407.

⁶⁵ Sandra Harding, "A Socially Relevant Philosophy of Science? Resources from Standpoint Theory's Controversiality" (2004) 19:1 *Hypatia* 25 at 32 [Harding, "Socially Relevant"].

⁶⁶ Sandra Harding. Introduction: Standpoint Theory as a Site of Political, Philosophic, and Scientific Debate. P.1 in *The Feminist Standpoint Reader* Ed. Sandra Harding. 2004 Routledge NY.

⁶⁷ Sandra Harding. *Whose Science? Whose Knowledge?* 1991. Cornell University Press

⁶⁸ *Ibid* at 26.

⁶⁹ *Ibid* at 29.

⁷⁰ *Ibid*.

⁷¹ These are not the only reasons for controversy, but they are prominent ones. Its Marxist origins are another. Sandra Harding, "Introduction: Standpoint Theory as a Site of Political, Philosophic, and Scientific Debate" in Sandra Harding, ed, *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies* (New York: Routledge, 2004) 1 at 1 [Harding, "Standpoint Theory"].

interested position, but is interested in the sense that it is engaged.”⁷² Hartstock emphasizes that we cannot deal with the use and misuse of power, *if we do not participate in exposing it*.⁷³

One may expose misuse of power from the inside, and I aim to expose aspects of the use and misuse of legal power in this manner in the chapters that follow. Notably, research methodologists Doucet and Mauthner⁷⁴ refer to the difficulty in defining what an “insider” in research is.⁷⁵ They state that, “at the core of standpoint epistemology is the assertion that the world can best be represented from a particular socially situated perspective, one which represents epistemic privilege or authority.”⁷⁶ This is not to say that by merely relating what I have experienced or seen, or recording what other caregiving mothers say they have seen or experienced I automatically privilege what is stated or seen, for as Harding points out, it takes more than this to identify and locate material and political forms of oppression, and to understand oppressive hierarchical structures.⁷⁷ However, in such feminist research, the ways in which scholars position themselves are understood to bear a relationship to claims of knowledge, and scholars are understood as present in the telling of theirs.⁷⁸

In my research, I abide by Canadian philosopher Lorraine Code’s view that women do, in fact, have situated knowledge, realized through their experiences in both social and institutional settings.⁷⁹ Clearly, motherhood is one setting, and courts and tribunals are another, in which feminist standpoints may evolve. The evolution of a feminist litigant standpoint is not a *new* phenomenon. In the 1880s, British activist Georgina Weldon litigated to change the *Lunacy Laws* used in conjunction with the doctrine of *couverture*, by husbands against their wives.⁸⁰ Legal scholar Kristin Kalsem states of Georgina Weldon that “she was the author of her own legal story. In the courtroom, in her writing, in her public performances – she was always representing herself.”⁸¹ Weldon herself stated of those on the other side of a case, “they also do their best to confuse me with the inextricable labyrinth of law, trying to get rid of me

⁷² Nancy C. M. Hartsock, “The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism” in Harding, “Standpoint Theory”, *supra* note 66, 35 at 36.

⁷³ *Ibid* at 37. She states standpoint positioning can expose relations among people as inhuman and thus has a liberatory role.

⁷⁴ Andrea Doucet & Natasha S. Mauthner, “Feminist Methodologies and Epistemology” in Clifton D. Bryant & Dennis L. Peck, eds, *21st Century Sociology, A Reference Handbook* (Thousand Oaks, CA: Sage, 2006) 36.

⁷⁵ *Ibid* at 40.

⁷⁶ *Ibid* at 37.

⁷⁷ Harding, “Socially Relevant” *supra* note 65 at 31

⁷⁸ According to, Laurel Richardson & Elizabeth Adams St. Pierre, “Writing: A Method of Inquiry” in Norman K. Denzin & Yvonna S. Lincoln, eds, *Handbook of Qualitative Research*, 3d ed (Thousand Oaks, CA: Sage, 2005) 959, a multitude of ways of knowing and telling now co- exist in post-modern projects, but also in others.

⁷⁹ Lorraine Code, *Rhetorical spaces: Essays on Gendered Locations*, (New York, NY: Routledge, 1995) [Code, *Rhetorical Spaces*].

⁸⁰ *Couverture* provided women’s interests be subsumed under those of their husbands. As such women had no legal right to property or money. *Couverture* has been described as a legal disability. It included a mother not having the right to legal custody of her children. *Black’s Law Dictionary*, 7th ed, *sub verbo* “*couverture*”.

⁸¹ Kalsem *supra* note 38 at 136.

at any price, but I stand up to them and I appeal and appeal and appeal.”⁸² Overtly conscious of law’s capacity in the guise of protection to trap and push married women, Weldon pushed back, making demands for legal rights in her case to change the legal ability of husbands to have their wives declared psychiatrically disabled for personal and financial gain, when they were not. Her views on her courtroom experiences would be very different than that of a male observer, even though male observers at the time commented that she, although not a lawyer, presented her case well.⁸³

For mothers with disabled children to present their cases well is no simple matter, for as Yi-Ting Shih⁸⁴ has stated, “mothers of disabled children may be viewed as a marginalized group whose perspectives can be easily neglected, since they are not men, not mothers of non-disabled children, not disabled persons, or not professionals.”⁸⁵ However, while this is so, Code claims women reposition themselves at the point where they have managed to reconstruct ‘meanings’ that have evolved from their experiences. According to Code, women participate in transformative strategies towards “a changed politics of care,” and I would add to that *a changed law of care*.⁸⁶

Mothers learn along different pathways. These include medical learning. For example, acquisition of the skills required to watch for subtle signs of a medical status of one’s child. One is through formal education targeting the mothers of ‘special needs’ children. It is well-documented that the mothers of severely disabled children become well-educated about their child’s disability.⁸⁷ They conduct research, attend information sessions, participate in private workshops and parenting conferences and, as nursing scholar Cheryl Gibson describes, ask pointed questions of their child’s physicians. This education provides mothers with specialized knowledge and the recognition of what the state will and will not take responsibility for. Kathy Levine’s word, ‘authoritative knowledge’, describes a form of knowledge that caregiving mothers of disabled children acquire.⁸⁸ Referencing Brigitte Jordan,⁸⁹ Levine states that “[t]he label of ‘authoritative’ is meant to draw attention to the status of knowledge of a social group. She adds

⁸² *Ibid* at 137.

⁸³ Kalsem, *supra* note 38 at 134-135.

⁸⁴ Yi-Ting Shih, *The Journey of Becoming and Being a Mother Raising a Disabled Child – The Transformations Between and Across Social Positions* (Doctoral Dissertation, Newcastle University, School of Geography, Politics and Sociology, 2012) [unpublished] online: http://fguir.fgu.edu.tw:8080/bitstream/039871000/11877/2/yiting_final.pdf.

⁸⁵ *Ibid* at 61.

⁸⁶ Code, *Rhetorical Spaces*, *supra* note 79.

⁸⁷ Cheryl H. Gibson, “Facilitating Critical Reflections in Mothers of Chronically Ill Children” (1999) 8:3 *Journal of Clinical Nursing*, 305; Kathy Levine, “Against All Odds: Resilience in Single Mothers of Children with Disabilities” (2009) 48 *Social Work in Health Care* 402 [Levine, “Against All Odds”].

⁸⁸ Kathy Levine, “Resilience and Authoritative Knowledge: The Experiences of Single Mothers of Children with Disabilities” (2008) 10:1 *Journal of the Association for Research in Mothering* 133 [Levine, “Resilience”].

⁸⁹ Brigitte Jordan, “Authoritative Knowledge and Its Construction” in Robbie E. Davis-Floyd & Carolyn F. Sargent, eds, *Childbirth and Authoritative Knowledge: Cross-Cultural Perspectives*, (Berkeley: University of California Press, 2007) 55, referenced in Levine, “Resilience”, *supra* note 88 at 133.

“the power of authoritative knowledge is not that it is right, *but that it matters*.”⁹⁰ Anna Karin Kingston states that her experiences with her son were parallel to those of her research participants.⁹¹ Like them, she observes, “I was also involved in legal proceedings against the department of education, which culminated in the High Court.”⁹² Kingston’s approach, the referencing of experiential knowledge and social location, is not uncommon in this area of research. Kingston is a professional, a researcher, a mother of a child with disabilities and a non-disabled child and also as a litigator suing the government of Ireland.

Standpoint theory claims that research cannot be neutral⁹³ and Kingston points out the non-neutrality of her research.⁹⁴ My view is that mothers’ knowledge is an important part of research overall, *and particularly disability research*. In the setting of her research on the knowledge and agency of mothers of children with chronic illness, Gibson claims “we live in a culture that has left the mother’s experience, the mother’s perspective, and the mother’s power, in the shadow.”⁹⁵ This includes a shadow having been cast over their legal experiences. My standpoint as a medically disabled female lawyer and longtime caregiving mother enters into my own research as well, for reasons I address below.

In this project, it is an individual (myself) whose *knowledge and understanding* of mothering a severely medically disabled child has an *experiential* component to it. Lorelei Carpenter and Helena Austin claim that caregiving mothers perceive themselves as differently situated than typical mothers,⁹⁶ with unique understandings derived from their social locations.⁹⁷ They state “the experience of living liminality facilitates the development of distinct orienting contexts for making-meaning and navigating intrapersonal and interpersonal experiences,” and that these “manifest[ed] in a reappraisal and reconstruction of maternal subjectivity”.⁹⁸

⁹⁰ *Ibid.* (My emphasis).

⁹¹ Anna Karin Kingston, *Mothering Special Needs: A Different Maternal Journey* (London: Jessica Kingsley, 2007) at 13 [Kingston, *Mothering Special Needs*].

⁹² *Ibid.*

⁹³ See Doucet & Mauthner, *supra* note 74.

⁹⁴ Kingston, “Maternal Power”, *supra* note 44 at 3. She states her personal experience was a great advantage to her in her research.

⁹⁵ C Gibson, *supra* note 87 at 310, referencing Naomi Ruth Lowinsky, *The Motherline: Every Woman’s Journey to Find Her Female Roots* (New York: Putnam, 1992).

⁹⁶ These authors emphasize the need to avoid essentializing any mothers, something that removes differences. Lorelei Carpenter & Helena Austin, “Silenced, Silence, Silent: Motherhood in the Margins” (2007) 13:5 *Qualitative Inquiry*, 660 at 670.

⁹⁷ Jennifer Kim Bateman, *Living Liminality: Maternal Subjectivity in the Context of Raising Children with Autism* (Doctoral Dissertation, University of Pennsylvania, 2011) [unpublished, archived at University of Pennsylvania, online <<http://repository.upenn.edu/dissertations/AI3463043>>] she describes mothers as having distinct orienting contexts of making-meaning, for example.

⁹⁸ *Ibid.* at 119.

Care scholar Jonathan Herring notes that care issues, in particular those concerning mothers, have been marginalized, including in academia.⁹⁹ He observes that the businessman, with rights of autonomy and freedom to contract, is well-situated and recognized in law. He adds, “[t]he exhausted mother of the disabled child, with little autonomy” or freedom is not. He further suggests that she is a legal anomaly: “Not even perhaps, of particular interest to lawyers.”¹⁰⁰

This anomalous aspect of the status of mothers with severely disabled children has yet to be accounted for legally. I build on the suggestions of Shih, Levine, and Code to demonstrate that caregiving mothers can and do use their knowledge to transform law, having commenced a collective, albeit fragmented, process with their individual (and less often group¹⁰¹) aims of transforming motherhood. I concur with Lorraine Code’s view that an ‘epistemic shift’ in institutional make-up can occur.¹⁰² Her belief acknowledges that presently, even though mothers do not always prevail in courts and tribunals, and even though their various forms of advocacy are not bringing about sought-after results rapidly, they are nonetheless instrumental in shifting the boundaries of ableist motherhood as an institution, and in transforming it through law.

Rather than experiential and subjective knowledge being central to a personal or intimate self-transformation as Levine describes, I construct as transformative mothers’ *changed consciousness and subsequent activism* as something that suggests acquired critical consciousness.

Now, I turn to present three features of my own standpoint, and do so by narrating salient features from my background, my experience of disability, and a few experiences and insights as a caregiving mother. Then, I explain my particular use of critical consciousness in this thesis.

My Standpoint

*Reflecting on “why it has taken so long for moral, political, and spiritual thinkers—who have written so much about so many things—to think deeply about disability issues ... It is...only when those who do the caretaking can also do the writing that this issue seriously comes to the fore.”*¹⁰³

My initial exposure to disability began with Jerry Lewis telethons. This was undoubtedly what led to my little sister Maggie, her kindergarten friend, Mia Sheard¹⁰⁴, and I to collect money for “the crippled children” in 1969. Our parents sent the money we collected and we were subsequently invited to visit the

⁹⁹ Jonathan Herring, *Caring and the law*. (Oxford: Hart, 2013) at 7.

¹⁰⁰ *Ibid* at 1.

¹⁰¹ For example, class action or when mothers together meet with their MPPs or protest at Queen’s Park.

¹⁰² Code, *Rhetorical Spaces*, *supra* note 79 at 118.

¹⁰³ Roger S. Gottlieb, “The Tasks of Embodied Love: Moral Problems in Caring for Children with Disabilities” (2002) 17:3 *Hypatia* 225 at 226.

¹⁰⁴ Name used with permission.

(then) Hospital for Crippled Children in Toronto.¹⁰⁵ My memories are of getting dressed up and later standing in a corridor, face-to-face with a young boy, who seemed to be about my age at the time. His legs were splayed, and he wore leg braces. A nurse told me that the boy had arthritis. I did not know then that I would go on to have severe inflammatory arthritis myself, nor that I would one day have a son with severe and chronic autoimmune illnesses.

At the time of that visit, I was a student at Rosedale Public School. Later, I attended a private school in southern Ontario and then, a Church of England grammar school for girls in London, England. I am privileged to have had a post-secondary education. After a short period of time studying French at the Sorbonne and working as an *au pair*, I earned a Bachelor of Arts degree from McGill University, followed by a qualifying year in sociology, also at McGill. Subsequently, I married and attended law school at The University of Detroit Mercy and The University of Windsor Law Schools. I have an M.A. degree in Critical Disability Studies, earned after I closed my law practice.

Further learning on my part occurred while working as a project coordinator and researcher in the Faculty of Health at York University, where I conducted thirty interviews with immigrant mothers of disabled children and twenty-eight interviews with stakeholders involved with caregiving mothers from across Canada. In 2011, I became a PhD student.

As noted, part of my personal background is that I have a moderately severe inflammatory condition, which arose after my marriage ended. As a single mother with a solo law practice, I struggled with my health, along with that of two of my three children. Eventually, I closed my practice as the result of a serious health crisis. As I was unable to afford the \$20,000 plus a year for the biologic agent my rheumatologist said I required, I spent a year bedridden, taking different disease-modifying drugs. When my body responded badly to these treatments, I joined a pharmaceutical trial for an injected and unlicensed drug, and participated in other medical research too. I learned how to manage bedside parenting.¹⁰⁶ Meanwhile, the Canadian Arthritis Patients Alliance (CAPA) advocated for me to access the biologic agent I needed, as did my specialists. CAPA members were in regular contact with one another,

¹⁰⁵ Tracy O'Dell, "Not Your Average Childhood: Lived Experience of Children with Physical Disabilities Raised in Bloorview Hospital, Home and School from 1960-1989" (2011) 26:1 Disability & Society 49, offers a perspective as a former resident at Bloorview during the era I visited.

¹⁰⁶ As I discuss in Chapter 6, there is data on increased prevalence of illness in mothers of children with severe disabilities based on a 2006 Statistics Canada study, "The Participation and Activity Limitation Survey (PALS) 2006: Technical and Methodological Report" (Ottawa: Author, 2007) online: Statistics Canada <<http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.htm#archived>> [Statistics Canada, "PALS: Report"]. There is also the evidence for this that comes through in my literature review. Court decisions provide strongest evidence, backed up with medical documentation and affidavits. For example, in *Morrison v Morrison*, 2001 YKSC 521, [2001] YJ No 50 (QL) [*Morrison*], the *mother* had severe diabetes which required a 24-hour-a-day insulin pump and she had diabetic retinopathy. Two of her four children were disabled. The judge emphasized the difficulty this mother had working three and a half days a week with her illness in addition to caregiving obligations and the lack of access exercised by the children's father. The latter is noted to be the reason this sick mother got very little respite.

media, politicians, and with me. The Arthritis Society (TAS) provided me with a social worker and with a physiotherapist who came to my home. I had a family doctor and a seasoned family lawyer, both of whom stood by me as I became sicker and more disabled. During this crisis, my former spouse, his wife and their lawyers went to lengths to portray me in a poor light as a wife, mother and lawyer. It was alternatively alleged that I was not sick or that I had always been sick. My athletic, outgoing non-disabled son, when faced with the choice, chose to remain with his siblings and with me, living as we were with disabilities of various kinds.

My dissertation is not about the plight of disabled mothers with disabled children in family law settings. However, having been a single mother with young children and a serious medical condition who has experienced protracted contested proceedings firsthand, specifically over disability-related support issues for myself and my children, it is part of my standpoint, as are my dealings with government agencies for supports. My history has provided me with insights into how disability support to mothers is seen and dealt with in both private and public contexts.

The discovery that two of my children had disabilities required me to seek out child experts.¹⁰⁷ It also required me to engage in expensive, time- and energy-consuming programs and practices, including during the time when I was trying to build my law practice, and later, when I was myself becoming ill. These demands required me to learn many new things. I met with special education teachers and became familiar with the workings of special education departments, from the inside. I attended Identification, Placement, Review Committees (IPRC) meetings and Individualized Education Program consultations. I met with school principals, attended educational testing sessions and experienced having a child in a self-contained segregated classroom for two years.¹⁰⁸ Many of the children who came over to play with my children had disabilities, and I connected with their parents. I appealed education-related test results and had disputes in the education system. I attended children's social skills groups, including the Centre for Addiction and Mental Health, (CAMH's) (then) group for children on the autistic spectrum.

Over the years, my children attended private and public schools, as we struggled to find a good fit. I learned that not all schools are equal, but overall, I found special education teachers to be wonderful people. I engaged private tutors and a private teacher. For a short time, along with their father, I also home-schooled my children.

I was taught to use puffers, and a chamber to administer medication to my son. I was taught in a hospital to use both the chamber and a nebulizer machine.¹⁰⁹ From age three, my son wore a rubber mask

¹⁰⁷ Andrew Solomon, *Far from the Tree: Parents, Children and the Search for Identity* (New York: Scribner, 2012).

¹⁰⁸ Mother's must become adept at negotiating special education issues. I learned that every aspect of my son's life was touched by his health conditions, including the task of learning to write. See Appendix C

¹⁰⁹ Appendix D shows how the nebulizer machine became integrated as part of life in our home.

attached by a tube to a machine to inhale his treatments at home, and when that was insufficient, in hospitals.

I learned how to identify when my son was medically in trouble. This was one of the many medical “lessons” in which I was “schooled” in a hospital setting. There were more learning curves to follow. I have had involvement over the years with: diagnoses of mild cerebral palsy, autism, immune disorder, neonatal sepsis, learning disabilities, herpetic esophagitis, and others. I attended children’s hospital clinics and wards; emergency rooms; autism centres; autism support groups; autism skills classes. I participated in research studies for mothers with disabled children. I met with hospital-based physicians: paediatricians; paediatric immunologists and ophthalmologists; gastroenterologists; infectious disease specialists, child psychiatrists; clinical child psychologists; home care nurses; public school and hospital clinic social workers and speech language pathologists (the latter for two of my children).

There were scans for esophageal reflux disease and tests for cystic fibrosis. I learned about, administered and consented to the use of strong and experimental paediatric medications on one of my children. I observed what medications did to my child, to his skin, his gut, to his mood and to his ability or inability to attend school. Over the years, I have fearfully watched the effects on him as his complex and life-threatening medical history unfolded. I have had a child speak to me about our times together, stating at different points, *“It was touch and go there for a while Mum, touch and go”* and, *“I died”*.¹¹⁰

Over the years I have sought out psycho-educational evaluations¹¹¹ and respite services, publicly and not publicly-funded. For years, I was attached to wall nebulizers containing Ventolin and steroids in hospital emergency rooms (usually between midnight and 4 a.m.) with a child wearing a green rubber mask over his nose and mouth sitting on my lap, sometimes kicking and screaming for the duration. For years, I administered antibiotic eye drops for my son’s eye sockets that frequently had pus draining from them. On these occasions, he was also prescribed pulsed dosages of dexamethasone to be administered at home. There were ongoing skin infections, boils, and abscesses and drainages. There were continual prescriptions to be filled; purchases of lost and run-out asthma puffers after midnight, oral and inhaled steroid medications, constant vigilance for medication compliance, suspensions from school, disputes about the suspensions from school, missed school and make-up lessons and sick notes and explanations, peanut allergy concerns and EpiPen teacher education in the schools (over many years).

These experiences weighed heavily on me. Like many other mothers, whatever was required, no matter how late at night, no matter how horrific, expensive or difficult to access – I, too, have been there. I have found it, I have done it, I have accessed it, I have bought it, and importantly, I have heard and witnessed it.

¹¹⁰ Appendix D also contains photos that held the possibility of being the last photos taken of one of my sons and my daughter receiving intensive care in hospitals.

I was fortunate in that I am comfortable speaking with professionals in medical and educational settings. This means I have been at relative ease speaking with professionals about my children's medical conditions. I was able to consult on treatment and diagnoses with medical personnel and with family members who were physicians, and I researched medical journals when problems arose. In addition, I often felt protected due to my having had legal training and having physicians in the family. Perhaps connected to these advantages, I have always trusted my instincts when my children were ill, and felt I could act on them.¹¹² Once, I telephoned a pediatrician at home at two in the morning, insisting to her husband that I had to speak with her immediately. This paediatrician told me that mothers' impressions were taken as part of the clinical signs. In other words, she relayed that my view comprised maternal medical knowledge.

The responsibility for care however, fell squarely on my shoulders. Prior to becoming sick myself, I had been physically and emotionally exhausted for years. In my efforts to hold onto my career, on more than a few occasions, I attended court for a client first thing in the morning on a contested matter after spending a night in surgery or a night in the ER with a very sick child, sometimes with my other children in attendance in their pajamas. I also did so when I, myself had spent an evening in an emergency room. Once, I was too tired to realize that I still had an intravenous shunt inserted in a vein taped on my right hand, until I was leaving my office for an appearance at the courthouse. Another lawyer's clerk pointed this out to me. That event was indicative of my state of body and of mind.

Perpetually fatigued and frequently called away, I worried whether my practicing law was unfair to my clients. In a crisis, a working mother could find help on short notice. When chronicity of illness of mother and child is the reality, it is a different matter.¹¹³ As Gibson notes "chronic illness requires an orientation to care that is different from episodic or acute care".¹¹⁴ Yet, somehow, one is expected to make it work.

My standpoint is a mixed one, with both privileged and under-privileged statuses informing it. I was trying to practice law because I had to support myself, but I also wanted to have a career, something that was clearly unrealistic under the circumstances. It was a reality with long-term legal implications concerning my own right to support, and later, the support of my youths.

¹¹² There is a small body of literature considering "maternal instinct" in the setting of mothering including mothering children with disabilities. See Toni Delany, *To Entrap and Empower: Maternal Responsibility in the Age of Neo-Liberal Health* (Doctoral Dissertation, University of Adelaide, 2011) [unpublished] at 200. Delaney in her interviews with mothers of children with congenital heart disease had one mother relay that she relies on her instinct to alert her to an 'impending' illness. *Ibid* at 202.

¹¹³ Sociologist Talcott Parsons wrote about the concept of the sick role. This role was circumscribed, however and those who are sick are expected to work towards becoming well. See discussion in Robert F. Murphy, *The Body Silent: The Different World of the Disabled* (New York: W.W. Norton, 1987) at 19.

¹¹⁴ C. Gibson, *supra* note 74 at 305.

Group Standpoint of Caregiving Mothers

Experiential knowledge also forms part of a larger group standpoint.¹¹⁵ My standpoint is my own, for as Shih notes, mothers of disabled children are a diverse group. Even so, caregiving mothers may share historical, geographical, political and legal spaces, as well as their being “subordinate to the same normative regime.”¹¹⁶ A crucial feature of any common standpoint among us is the change in consciousness we undergo in our roles as mothers who seek to redefine the institution of motherhood in a manner that reflects justice for ourselves and for our disabled children. The end result of all of these experiences combined was unique ‘knowledge’ that was anything but “a view from nowhere.”¹¹⁷ I have been reluctant to reflect on places and times where my knowledge grew most. I questioned whether the inclusion of my experience in my thesis would make an appreciable difference to what I hope to achieve here. I told myself, ‘I am studying law and there can be no meaningful relationship between what I experienced as a mother and a doctoral project in law.’ Furthermore, I have long been aware that some memories, even after many years, still engender uncomfortable reactions when I reflect on them. It has been easy for me to appreciate how profoundly my son’s illnesses have impacted on who he is.¹¹⁸ However, it has been more difficult to acknowledge how his illnesses informed my identity. This is true, even though he and I were in this together. Caregiving mothers socialize, attend workshops and lectures together. They share literature and advice. We caregiving mothers who used to socialize still do so, even though our children are now adults. We also shared experiences with one another that we felt no one else could ‘get’. In a moment of great distress a leader in one support group stated that “we” beg CAS to take our kids, but they refuse. The word ‘we’ was expressed from a group position and we knew she did not mean it and we understood why she said it (and none of us wanted to give up our children). Something else occurs when one is frequently bed-side with one’s medically complex child. One is referred to as “Mom” by medical teams. Sometimes it felt like a form of erasure. It was disempowering. Caregiving advocate Donna Thompson has blogged about her request that this practice stop in the case of her attendance at medical meetings for her disabled son Nicholas. In my case, I felt its use alluded to a

¹¹⁵ Doucet & Mauthner, *supra* note 62 at 37.

¹¹⁶ Shulamit Almog & Lotem Perry-Hazan, “The Ability to Claim and the Opportunity to Imagine: Rights Consciousness and the Education of Ultra-Orthodox Girls” (2011) 40:2 *JL & Educ* 272.

¹¹⁷ Donna Haraway, *Simians, Cyborgs and Women: The Reinvention of Nature* (New York: Routledge, 1991) referenced in Doucet & Mauthner, *supra* note 62 at 38.

¹¹⁸ The impacts of severe chronic illness on children and on caregiving mothers are still something we are learning about. See Samantha Sartain, R. Heyman & Charlotte Clarke, “Hearing the Voices of Children with Chronic Illness” (2000) 32:4 *Journal of Advanced Nursing* 913; Ronald T. Brown et al, “Single Parents of Children with Chronic Illness: An Understudied Phenomenon” (2008) 33:4 *Journal of Pediatric Psychology* 408. This article notes it is mothers usually who provide care and that that burdens of it led mothers to identify as exhausted, referencing Elissa Epel et al, “Accelerated Telomere Shortening in Responses to Stress” (2004) 101:49 *Proceedings of the National Academy of Sciences of the United States of America* 17312, for the position that this exhaustion is expressed as advanced aging in care giving mothers at the cellular level.

‘medical mum’ and that a medical mom was a woman who alternately had all the power and none of the power in the care of her very sick child. Sometimes we felt empowered, other times we did not. Our standpoint as a group was that we were mothering in a parallel world to other mothers. We found it more intense, more fraught with risk, more precarious and more judged. At the same time we saw ourselves as fighters and we have all maintained that sense all these years later. We felt that being in a parallel world re-rendered us that way. Group standpoint helps to explain how the autism litigation got off the ground.

Reflexivity and Researcher Accountability

Doucet and Mauthner suggest that the requirement for reflexivity “is largely a point of consensus” in feminist research.¹¹⁹ They comment that reflexivity, “also refers to actively reflecting on personal, interpersonal, institutional, pragmatic, emotional, theoretical, epistemological and ontological influence on our research and interpretation processes” and they state it is equally relevant in areas such as data analysis.¹²⁰ Reflexivity is relevant here because it relates to the role of the researcher in ‘constructing’ knowledge.¹²¹ Doucet and Mauthner also assert that reflexivity is tied to researcher accountability. In light of the above, it goes without saying that my interpretation of material I examine has been filtered through my own subjectivity, which has evolved over the past years.

Like many other mothers who have conducted research about the adverse social construction of their role, and the ramifications of that, my interest in and my relationship to other mothers and disabled children have their origins in my experience. It would not be possible for me to set that aside. In any event, Chantell Burrows asserts that “the legal conceptualization of motherhood should reflect the social experience of mothers.”¹²² She points out that “it is crucial that societal and legal doctrines of motherhood coincide to present a comprehensive understanding.”¹²³ She references Fineman for advancing the position that even though mothers are poorly represented legally and politically, their views are nevertheless crucial in proposals in the areas of policy and law.¹²⁴ With this in mind, I next discuss the conceptual framework of critical consciousness.

¹¹⁹ Doucet & Mauthner, *supra* note 62 at 41.

¹²⁰ *Ibid* at 42.

¹²¹ *Ibid* at 38.

¹²² Chantell Louise Burrows, *Deconstructing Motherhood: A Critique of the Legal Regulation of Surrogacy* (MJur Thesis, Durham University, 2011) [unpublished, archived on Etheses Durham University, online: <<http://etheses.dur.ac.uk/3192/>>] at abstract (np).

¹²³ *Ibid*.

¹²⁴ Martha Albertson Fineman, “Images of Mothers in Poverty Discourses” 1991 Duke LJ 274.

Critical Consciousness

Consciousness *per se* has been discussed widely in legal literature and forms the foundation of critical legal theory.¹²⁵ American Supreme Court Justice Ruth Bader Ginsburg examined the question of “awakening consciousness in law schools” with regard to women’s treatment by law over 40 years ago.¹²⁶ Other scholars, such as Sheila Rowbotham,¹²⁷ Adrienne Rich¹²⁸ and Patricia Collins have considered women’s consciousness.¹²⁹ It has been described as an awakening process by both Ginsburg and Collins, and as an arising process by Collins.

I distinguish between becoming more aware and critical consciousness. The former can happen in any number of ways.¹³⁰ The latter comes about through learning, and the cognitive process of problematization. For Freire, the term conscientizacao refers to learning to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality.”¹³¹ Referencing Freire, Maritza Montero describes critical reflection as leading to new meaning. New meanings erode “uncritical acceptance of ideologies”¹³² and uncover myths.

Importantly, problematization has been described as a method of ‘breaking mythology.’¹³³ In my research, I am particularly interested in problematization and the exposing of myths present in legal determinations involving caregiving mothers.

Feminist legal scholar Fran Olsen describes the structure of consciousness as comprising a shared vision of the world, giving the example of the dichotomy of a ‘market’ versus ‘family’ vision that “underlies a society’s culture and also shapes the society’s view of which social relationships are “natural” and, therefore, which social reforms are possible.”¹³⁴ Olsen’s idea is useful to my project. One may

¹²⁵ As ‘legal consciousness’ and there is also reference to ‘critical legal consciousness.’

¹²⁶ Ruth Bader Ginsburg, “Treatment of Women by the Law: Awakening, Consciousness in Law Schools” (1971) 5:2 Val U L Rev 480 at 480.

¹²⁷ Sheila Rowbotham, *Woman’s Consciousness, Man’s World* (London: Verso, 2015).

¹²⁸ In Mary S. Strine, “The Politics of Asking Women’s Questions: Voice and Value in the Poetry of Adrienne Rich (1989) 9:1 Text & Performance Q 24.

¹²⁹ Patricia Hill Collins, “Learning from the Outsider Within: The Sociological Significance of Black Feminist Thought (1986) 33:6 Social Problems S14, online: Special Theory Issue <<http://www.cirtl.net/files/Hill-Collins1986,1990.pdf>>.

¹³⁰ Several authors emphasize that critical consciousness in its prompting of action and equipping oppressed persons to engage in conflict is qualitatively different from consciousness-raising. Critical consciousness brings with it a quality of authority, which lends itself towards activities that promote liberation according to Maritza Montero. Maritza Montero, “Methods for Liberation: Critical Consciousness in Action” in Maritza Montero & Christopher C. Sonn, eds, *Psychology of Liberation: Theory and Applications* (New York: Springer, 2009) 73 [Montero, “Methods for Liberation”].

¹³¹ Paulo Freire. *Pedagogy of the Oppressed* [Pedagogy]1986 (New York Continuum, 1970).

¹³² *Ibid.*, at 75.

¹³³ Freire states that the ordinary person is crushed, diminished, and maneuvered by myths and that the greatest tragedy is the domination of oppressed person by myths. Paulo Freire, *Education for Critical Consciousness* (New York: Seabury, 1974) at 5 [Freire, *Education*].

¹³⁴ Frances E. Olsen, “The Family and the Market: A Study of Ideology and Legal Reform” (1983) 96:7 Harv L Rev 1497 at 1498 [Olsen, “Market”].

extrapolate and theorize that the dominant meanings ascribed to childhood are likewise structures of consciousness. i.e., shared societal notions respecting what childhood should look like and lead to. The dominant view of children as ‘becomings’ and, in the investment state, future taxpayers, is a largely shared societal vision for example. ‘Mothering’ as relationship is genericized without reference to severely disabled children.

Shared visions do not always remain shared though, including with respect to the assumed ‘natural’ mother and ‘normal’ child and indeed, shifts in mothers’ consciousness have been documented as arising through the experience of having a disabled child. In this experience, mothers may cease to share society’s vision of motherhood and concomitantly, childhood. The “culture of silence”¹³⁵ as to the realities of caregiving mothers’ lives plays a role in mothers turning away from the dominant structure of consciousness. The process of deviating from shared consciousness that Olsen,¹³⁶ a feminist legal scholar, refers to corresponds with the development of critical consciousness in my use of the term in my project.

Paolo Freire, who theorized critical consciousness, claimed that education was central to the acquisition of a form of critical consciousness. Considering this, I myself theorize that the formal and informal “education” that mothers with disabled children receive likewise triggers the process of *conscientization*.¹³⁷ According to Montero, problematization can be generated without set techniques.¹³⁸ It is apparent that mothers become adept at “reading” and “hearing” the meta-message of what ableist social agents tell them. They also become adept at “learning” from external constructions of their experiences. I theorize the *status quo* is challenged by mothers when they perceive their and their children’s care and support have reached an intolerably low threshold. When they become aware their circumstances are impossible, wrong, harmful or unjust *and they have the agency to do so*, they challenge expectations. For example, American actress Marianne Leone describes her required attendance at “Early Intervention” state-run classes held for “CP Kids”¹³⁹ and their mothers in New York in the 1980s.¹⁴⁰ The program offered physical therapy, speech therapy and occupational therapy, as well as social worker support. Leone found that the ‘mothering’ education wasted her time, and moreover, that she was being asked to

¹³⁵ From Sheila Rowbotham’s, *Woman’s Consciousness, Man’s World*, *supra* note 145 at 29: “When the conception of change is beyond the limits of the possible, there are no words to articulate discontent so it is sometimes held not to exist. This mistaken belief arises because we can only hear silence in the moment in which it is breaking.”

¹³⁶ Olsen, “Market”, *supra* note 134 at 1498.

¹³⁷ Whereas in Freire’s project, *Pedagogy of the Oppressed* (New York Continuum, 1970) [Freire, *Pedagogy supra* 131], the state denied men the ability to read and therefore to become politically aware, caregiving mothers are conversely urged to accept teachings they may not want, for reasons having to do with compliance with state objectives, e.g. by attending workshops such as those for managing “normal” behavior, described in David Farrugia, “Exploring Stigma: Medical Knowledge and the Stigma of Parents of Children Diagnosed with Autism Spectrum Disorder” (2009) 31:7 *Sociology of Health and Illness* 1011 at 1021.

¹³⁸ Montero, “Methods for Liberation”, *supra* note 130 discussions at 80 and 81.

¹³⁹ This is a colloquial expression that refers to children with cerebral palsy.

¹⁴⁰ Marianne Leone, *Knowing Jesse: A Mother’s Story of Grief, Grace and Everyday Bliss* (New York: Simon & Schuster, 2010).

participate in approaches to treatment she disagreed with. In response, she wrote a controversial article in *Exceptional Parent* called “Early Interference.”¹⁴¹ The title reveals how she had problematized, reinterpreted and reframed what she had experienced. Unlike the emancipatory education described by Freire in his book¹⁴² that is designed to elicit self-liberation, the education for mothers of disabled children Leone critiques is designed to train mothers in how to think about disability and how to manage their children’s conditions. It is mothers reflecting upon and questioning or resisting such education that lays the groundwork for the evolution of their critical consciousness.¹⁴³ This description is also in keeping with Kathleen Weiler’s feminist adaptation of Freire’s pedagogy of the oppressed. Weiler asserts that “teachers are not always on the same side as [the] oppressed” learners.¹⁴⁴ Moral philosopher Mustakova-Possardt¹⁴⁵ asserts that a variety of experiences may place one along a pathway to critical consciousness and that having a disabled child may itself constitute one such experience.

Another “education” mothers receive is arrived at through experience with litigation. While it is clear that it is through problematization that most mothers end up in front of a judge asking for support for their disabled child, it is also the case that there are valuable lessons learned at each stage of a legal proceeding. A further feature of critical consciousness may include the formation of a new identity, by becoming a caregiving mother litigant, for example.¹⁴⁶ The process towards critical consciousness is also noted to accompany a sense of responsibility for others.¹⁴⁷

Liberation is the goal of those seeking social change. The violence from which people seek to be liberated includes “structural violence”,¹⁴⁸ which I argue includes constraints provided by unjust and gendered law. With critical consciousness, injustice is acted upon as a result of a new-found sense of agency, and with the exercise of this comes empowerment.¹⁴⁹ Melanie Panitch,¹⁵⁰ Margaret Newman¹⁵¹

¹⁴¹ *Ibid* at 57. Maria Mutch, in *Know the Night. A Memoir of Survival in the Small Hours* (Vintage Canada, 2015) at 61, wrote “Gabriel learned to use the Picture Exchange Communication System (PECS), which was developed for people with speech and language problems. Through Workshops I learned how to use the program so I could implement it at home, and then his staff at school learned as well.” When her son threw the tablet, she understood that he was yelling.

¹⁴² Freire, *Pedagogy*, *supra* note 131.

¹⁴³ I do not mean to suggest that those women providing therapeutic treatment to children and classes to mothers deliberately went out of their way to oppress. The problem being pointed out is systemic, where those with severe disabilities feel less valued and are less respected.

¹⁴⁴ Kathleen Weiler, “Freire and a Feminist Pedagogy of Difference” (1991) 61:4 *Harvard Educational Rev* 449 at 454.

¹⁴⁵ Elena Mustakova-Possardt, *Critical Consciousness: A Study of Morality in Global, Historical Context* (Westport: Praeger Publishers, 2003) [Mustakova-Possardt, *Study of Morality*].

¹⁴⁶ Elena Mustakova Possardt, “Critical Consciousness: Motivation for Service to Humanity” (Keynote address delivered at the Baha’i Conference on Social and Economic Development in Orlando, FL., 12-18 December 2004) [unpublished] [Mustakova-Possardt, “Motivation for Service”].

¹⁴⁷ Hence Leone’s felt need to publish her views on what she, as the mother of a boy with a severe disability was being taught by the state of New York.

¹⁴⁸ J. Christie, “Preface” in Montero & Sonn, *supra* note 130, at vii.

¹⁴⁹ Mustakova-Possardt, “Motivation for Service”, *supra* note 146 at 11.

and Elena Mustakova-Possardt¹⁵² reference critical consciousness in their work on mothers with disabled children, independently of one another. Panitch, a social worker by training, employs a social work orientation, describing the community and political activities of Canadian mothers of children with intellectual disabilities. She asserts that her descriptions demonstrate an evolving socially-oriented maternal critical consciousness.¹⁵³ Mustakova-Possardt, a psychologist by training, focuses on the psychological and moral evolution of critical consciousness as part of the social growth and personal transformation of a Bulgarian mother with a severely disabled daughter.¹⁵⁴ Mustakova-Possardt presents sections of her interview with a mother who acquired a “mature degree” of critical consciousness in her orientation towards her daughter and towards a society that Mustakova-Possardt describes as ableist, classist and sexist. Both Panitch, writing in Canada, and Mustakova-Possardt, writing in Bulgaria, name ableism as a systemic force that has a powerful effect on consciousness of and in motherhood.¹⁵⁵

In *Health as Expanding Consciousness*, Newman references graduate student research entitled *Patterns of Health in Mothers of Developmentally Disabled Children*.¹⁵⁶ Of mothers with disabled children Newman observes that they “embrace their present situation and allow themselves to be

¹⁵⁰ Melanie Panitch, *Accidental Activists: Mothers, Organization and Disability* (Doctoral Dissertation, City University of New York, 2006) [unpublished] [Panitch, *Accidental Activists* (Dissertation)] at iv, 9.

¹⁵¹ Margaret Newman, *Health as Expanding Consciousness*, 2d ed (Lincoln, NE: National League for Nursing Press, 1999)

¹⁵² Mustakova-Possardt, *Study of Morality*, *supra* note 145 at 120.

¹⁵³ Melanie Panitch, *Disability, Mothers and Organization: Accidental Activists* (New York: Routledge, 2008) [Panitch *Accidental Activists* (Book)]. This includes their involvement in litigation. At 149, she describes Paulette Berthiaume’s walkout of mothers from a courtroom during the Shadley Inquiry in the Quebec Superior Court. Earlier, at 120, Panitch explains that mothers engaged in illegal activity, “kidnapping” disabled residents from institutions in Quebec during this era. This reveals mothers having considered the law in relation to disability, and realizing it was not serving the interests of disabled persons and then engaging in civil disobedience.

¹⁵⁴ Mustakova-Possardt, *Study of Morality*, *supra*, note 145 at 34. She describes mature critical consciousness as the ability to critically and systematically reason and to link individual phenomena and patterns with the social order. See also the discussions in *ibid* at 123-124.

¹⁵⁵ Similarly, Elaine A. Jones, in *Social Reality Versus Family Law: The Experience of Mothers of Children with Long Term Disabilities* (Master’s Thesis, University of New Brunswick Saint John, 2002) [unpublished, archived on Researchgate, online:

<http://www.researchgate.net/publication/266349256_SOCIAL_REALITY_VERSUS_FAMILY_LAW_The_Experience_of_Mothers_of_Children_With_Long-Term_Disabilities>], discusses mothers with disabled children who are separating and divorcing acquiring an appreciation of the ramifications of being responsible for caregiving as undergoing a change in consciousness. Jones states that a goal in her MA was to raise consciousness in the legal community as to the plight of such mothers, *ibid* at 26. One of her concerns is that the family law community has insufficient experience with disability in their practices to be able to adequately address the long-term financial implications of this kind of care at separation. Implications she describes are “perpetual motherhood” and the “protracted obligations” that accompany it.

¹⁵⁶ M.C. West, *Patterns of Health in Mothers of Developmentally Disabled Children* (Master’s Thesis, Pennsylvania State University, 1984) [unpublished] referenced in Newman, at 68.

transformed by it. [They] ...were able to go beyond themselves and beyond reason into a new order of reality, *a new level of consciousness*.”¹⁵⁷

It is clear that for some caregiving mothers, advancing social change is important.¹⁵⁸ Work produced by mothers and those working closely with mothers from social science,¹⁵⁹ from critical disability studies,¹⁶⁰ and from disciplines other than law suggest that a range of profound changes take place in mothers’ thought in seeking disability supports. I am suggesting that in the process of their litigation, there are signs of changes in maternal consciousness.¹⁶¹ Empowerment can come about as a result of different confrontations with the legal and care systems. At the same time caregiving mothers can be disempowered. Indeed, a litigating mother can be both empowered and disempowered over the course of a single legal proceeding. Experiences of disempowerment can provide impetus to further resist.¹⁶² Different terms have been used to describe transformations, of various kinds.¹⁶³

¹⁵⁷ Richard Moss, *The I That Is We: Awakening to Higher Energies Through Unconditional Love* (Berkeley: Celestial Arts, 1981) quoted in Newman, *supra* note 151 at 68.

¹⁵⁸ Maurina Beadle’s words suggest an example of a mother litigating in the justice system, who has acquired changed consciousness about her circumstances *vis-à-vis* the state. When the Federal government made it clear it did not want to pay for her son to live at home, suggesting he be placed in an institution, possibly out of province, she stated to the press “When reporters ask me what I’ll do if Jeremy is moved to an institution, I tell them, ‘Over my dead body. He won’t get no love in an institution.’” She also revealed “It didn’t occur to me that when he ran into a situation that fell under Jordan’s Principle that [the funding] would be so hard to access.” When she had the realization that neither she nor her son were being treated well in law, she brought a lawsuit against the government in the Federal Court. See Moira Peters, “It’s a Matter of Jordan’s Principle: Canada’s Healthcare System Leaves Native Child Behind” *The Dominion* (5 October 2011) online: <<http://www.dominionpaper.ca/articles/4180>>. The case was eventually brought to the Federal Court of Appeals, *Canada (AG) v Pictou Landing First Nation*, 2014 FCA 21, 456 NR 365, The government filed a notice of Discontinuance (11 July 2014).

¹⁵⁹ See e.g. Shih, *supra* note 84, and Delany, *supra* note 128.

¹⁶⁰ See e.g. Kate Scorgie & Dick Sobsey, “Transformational Outcomes Associated with Parenting Children with Disabilities” (2000) 38:3 *Mental Retardation* 195.

¹⁶¹ Vanessa Ruth Fishwick, *A Literature Review into Parents’ Experiences of Raising a Child with a Disability and Research Exploring Mother’s Experiences of Receiving a Diagnosis of Monosomy IP36 Deletion Syndrome for their Child*. (Doctoral Dissertation, School of Psychology, University of Birmingham, 2009) [unpublished, archived on Etheses Birmingham University, online: <<http://etheses.bham.ac.uk/383/>>] at 25, refers to the acquisition of a philosophy of the present. She draws from the term used in Pamela Fisher & Dan Goodley, “The Linear Medical Model of Disability: Mothers of Disabled Babies Resist with Counter Narratives” (2007) 29:1 *Sociology of Health & Illness* 66 at 74. This represents a shift in orientation.

¹⁶² The disempowerment of women in situations that matter to them has been described creating dissatisfaction and fueling civil unrest. See Regina Scheyvens & Leonad Lagisa, “Women, Disempowerment and Resistance: An Analysis of Logging and Mining Activities” (1998) 19:1 *Singapore Journal of Tropical Geography*, 5.

¹⁶³ For example, Susan Kaye Tarrant, *The Maternal Metamorphosis: Experiences of Fourteen Women Parenting Children with High Functioning Autism in North Central Victoria* (Doctoral Dissertation, La Trobe University, 2002) [unpublished, archived by Trove, online: <<http://trove.nla.gov.au/work/32549531?versionId=39582861>>] referenced incompletely in Bateman, *supra* note 105, refers to maternal metamorphosis. Other examples are Scorgie & Sobsey, *supra* note 160, who refer to changes in parents as transformation; Shih, *supra* note 84 refers to transformations and journeys; Margaret H. Vickers & Melissa A. Paris, “Towards Ending the Silence: Working Women Caring for Children with Chronic Illness” (2005) 17:2 *Employee Responsibilities and Rights* 91, refer to the recreation of one’s authentic self; Bateman, *supra* note 105, refers to transformed subjectivity; Valmae Anne Ypinazar, *This Is Our Life. This Is Our Child. Mothers Dancing in the Margins of Disability* (Doctoral dissertation, James Cook University, School of education, 2003) [unpublished, online: <<http://researchonline.jcu.edu.au/1181/>>]; Newman, *supra* note 151, and, Levine, “Resilience”, *supra* note 76, all refer to personal transformations; Patricia A.

According to Gibson, ultimately, it is the recognition of frustration that forces mothers to critically examine their circumstances.¹⁶⁴ Gibson's study, which focuses on the role of frustration in empowerment, supports an aspect of Fraser's theory of status misrecognition. Gibson observes that in advocating for their chronically ill children, caregiving mothers move into positions of participatory competence, allowing them to be heard by those in control.

However, only Panitch's description of conscious and oppositional motherhood, situated in the experience of mothers with disabled children,¹⁶⁵ and Mustakova-Possardt's description of critical consciousness in the setting of a mother with a daughter with Down Syndrome and a spinal disability¹⁶⁶ correspond to the form of transformation I rely on here. Mustakova-Possardt's chapter on Emily, the young mother of a severely disabled daughter, states "Emily reflects the transition to the intellectual, moral and spiritual integration of authentic consciousness...Emily has challenged practically every social norm and has brought herself double stigma...".¹⁶⁷ Both scholars' descriptions include caregiving mothers with views different from those of mainstream society with respect to equality and discrimination.

Although I am unable to make any direct claims about specific litigating mothers' acquisition of critical consciousness, given that mine is not an empirical study, I can claim that features of it may be perceived in the words and activities of mothers whose names and cases arose in the course of my research. Therefore, I only suggest aspects of changed consciousness in the setting of maternal disability activism. Examples of changed consciousness are also seen in Panitch's work (which was empirical, involving interviews) and also in that of Mustakova-Possardt. Mustakova-Possardt describes a caregiving mother she interviewed as continually searching for meaning and referring in interviews to living in an alternative social reality. This mother is further described as engaged in critical dialogue about socio-cultural practices with respect to her disabled child and societal views that she deems oppressive; she referred to her own version of 'justice' and 'equity', according to her interviewer.¹⁶⁸ I draw from their observations in my interpretation.

Douglas, *Governing Lived Embodiment: Autism, Asperger's and Care*, (Masters Thesis, Graduate Department of Sociology and Equity Studies in Education, Ontario Institute for Studies in Education, University of Toronto, Ontario, 2010) [unpublished, online: <https://tspace.library.utoronto.ca/bitstream/1807/24225/1/Douglas_Patricia_N_201003_MA_thesis.pdf>], refers to identity by conscience of self-knowledge; Levine, "Against All Odds", *supra* note ##, to chosen mothers; Rita Black Monsen, "Mother's Experiences of Living Worried when Parenting Children with Spina Bifida (1999) 14:3 J Pediatric Nursing 157 at 157, to transformed parenting; Jones, *supra* note 155, to women's consciousness; and Toni Delaney, *supra* note 122, refers to resistance.

¹⁶⁴ *Ibid* at 306-307. One mother, who managed a business as well as provided care, described herself as losing faith. She reports not being "pushed around" in her professional life, but being pushed around as a caregiving mother.

¹⁶⁵ Panitch, *Accidental Activists* (Book), *supra* note 153, at 149.

¹⁶⁶ Mustakova-Possardt, *Study of Morality*, *supra* note 145 at 122.

¹⁶⁷ *Ibid* at 120.

¹⁶⁸ *Ibid*.

My claim is that mothers, in speaking their realizations and understandings through the medium of law and politics, can foster social reform.¹⁶⁹ Biographical sketches demonstrate this in relation to what I perceive to be changed consciousness. British Columbia's Sabrina Freeman is an example of a mother who may be described as exhibiting some features of critical consciousness.¹⁷⁰ Freeman, who holds a PhD in sociology, was *guardian ad litem* for her daughter, Michelle Tamir, in the *Auton* litigation at the Supreme Court of Canada.¹⁷¹ Prior to the lawsuit, Freeman managed Families for Early Autism Treatment Centre (FEAT) in Vancouver.¹⁷² While running FEAT and demanding services for her daughter from the British Columbia government, Freeman may be described as having experienced "the force of restructured consciousness" described by theorist Montero.¹⁷³

Montero states that one response to the force of restructured consciousness is a willingness to engage in conflict and to make use of available resources to change society. It is the force of this restructured consciousness which enables individuals to set out their demands.¹⁷⁴ Freeman is an author, speaker and blogger ("The Autism Pundit"), now working in the area of international autism awareness, advocacy and education.¹⁷⁵

Nova Scotia's Joyce Dassonville also provides an example of a mother whose activities suggest changed consciousness. Dassonville practiced law for over a decade, working in disability, health and family law litigation. For several years, she was a hearing officer for appeals of workers compensation support claims. She also spent years advocating and litigating on behalf of herself and her severely disabled daughter. She states that her "professional experiences gave her the background necessary to get the job done. Her professional skills proved useful in handling all the health, education, and legal issues

¹⁶⁹ See Susan Hekman, "Reply to Harstock, Collins and Smith" in Harding ed, *supra* note 66, 269 at 271.

¹⁷⁰ Mustakova-Possardt, "Motivation for Service", *supra* note 146, describes pre-critical consciousness, transitional critical consciousness and mature critical consciousness.

¹⁷¹ Parents and children challenged the province's refusal to fund services to autistic children, claiming such refusal infringed the equality rights of autistic children. The Supreme Court of Canada ruled that government funding for care that was not a core service was not protected under s 15(1) of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11 [Constitution]. LEAF as an intervenor argued that failure to provide such services to girls mean that they were placed at increased risk of sexual abuse. Women's Legal Education and Action Fund, "Auton et al v. British Columbia" online: LEAF <<http://www.leaf.ca/auton-et-al-v-british-columbia/>>.

¹⁷² According to Manfredi & Maioni, *supra* note 6, before becoming involved in the *Auton* lawsuit, and before she founded and became the Executive Director for her LOVAAS treatment centre (LOVAAS is form of intervention for autistic children), The position of her organization, FEAT, was that the refusal of the provincial government to fund LOVAAS therapy infringed laws in place to protect the rights disabled persons. FEAT BC's position was that the B.C. government's refusal to recognize the treatment as a medically necessary service provided through the province's health care system contravened "several laws designed to protect the rights of the disabled," *ibid* at 120. She was considering rights prior to the *Auton* litigation, of which she eventually became a party, along with her daughter.

¹⁷³ Maritza Montero, "Consciousness Raising, Conversion, and De-Ideologization in Community Psychosocial Work" (1994) 22:1 Journal of Community Psychology 3 at 9 [Montero, "Consciousness Raising"].

¹⁷⁴ *Ibid*.

¹⁷⁵ Freeman was awarded Queen Elizabeth's 50th Golden Jubilee Medal for legal and other advocacy on behalf of autistic children, all of which reflect critical consciousness as described by Panitch and Mustakova-Possardt.

that arose when caring for a child of her own, with autism.”¹⁷⁶ While in British Columbia, Dassonville stated on the FEATBC online discussion board “As I am going to commence this action on behalf of my daughter anyway, I will be happy to assist other families to do the same, at a significantly reduced cost from my (and other lawyers’) normal fee.”¹⁷⁷ Dassonville placed a sample letter for others to use on this same discussion board in their demands of government for funding.¹⁷⁸

Turning to a non-Canadian, Ireland’s Dr. Anna Kingston likewise qualifies as a mother who changed through advocating for her disabled child and working with other mothers doing the same. Her book’s title¹⁷⁹ refers to mothering disabled children as *a different maternal journey*; one she describes as ending at times with mothers suing the state due to “strong maternal conviction.”¹⁸⁰ Kingston also describes the need to “emancipate mothers” and urges that “feminists should build upon this emerging change of consciousness”¹⁸¹ and that is what I aim to do in writing this dissertation.

Conclusion

In this chapter, I have provided details about my research methods, including the reasons why I chose to follow the research pathway described above. This information provides a foundational framework for this research to the reader. In the next chapter, I review literature that informs my analyses and arguments concerning the legal rights of mothers with severely disabled children to support.

¹⁷⁶ Joyce Dassonville & Ehren McDow, “The Picture Cookbook. Four Volumes of Recipes for the Special Chef” (Vancouver: Granville Island Publishing, 2008) online: original link no longer available, see <http://granvilleislandpublishing.com/our_titles/cooking/the_picture_cookbook.html>.

¹⁷⁷ Joyce Dassonville, FEATBC Discussion Board. Archive 6, 2003, online: <<http://www.featbc.org/chat/messages/16/46.html?1104200469>>. The action she refers to is her *Charter* case against BC, that ended with the *Auton* decision. FEAT stands for Families for Early Autism Treatment of BC. (discussion board became private since I accessed this, waiting to hear if I may register.)

¹⁷⁸ *Ibid.*

¹⁷⁹ Kingston, *Mothering Special Needs*, *supra* note 91.

¹⁸⁰ Kingston, “Maternal Power”, *supra* note 44 at 8.

¹⁸¹ *Ibid.*

CHAPTER THREE: Review of the Literature

Introduction

This review addresses the literature informing my analysis of the legal right to support of mothers with severely disabled children. I begin with literature central to this project - that of legal rights, important to my discussions in Chapters Four, Six, and Seven. Then, I address the literature concerning mothers' social, economic and legal locations in society, followed with a review of the feminist literature on privatization of care and then, a discussion of the literature about disabled children. Each of these sections is relevant to the entire dissertation.

My review follows the order it does because I argue it is the combination of the present conceptualizations of rights as individual, rather than relational, along with the social and political positioning of caregiving mothers in neo-liberal and state investment politics, that together, have led to the cobbling together of an inadequate and indeed dangerously unstable 'system' of supports.

The Legal Rights Literature

As noted in my arguments section, I refer to rights to capture not only statutory rights to bring a claim for support (statutory entitlements), but also benefits (though not technically 'rights'), rights-claims or arguments made to persuade decision makers that there ought to be legal rights to needed forms of support subject to force of law, rights guaranteed by the *Charter of Rights and Freedoms*, international human rights, and finally, relational rights.

Few academics have examined the legal rights of mothers with disabled children to state support in any of these areas.¹⁸² Bridgeman, Manhas, Goodman, Herring, and Sossin are among the handful of legal scholars who have.¹⁸³

Within the area of state support to caregiving mothers, still fewer scholars have examined the important area of disabled child custody loss through law pertaining to the provision of housing, care and treatment support available to caregiving mothers. In an Alberta Law Review article, Gwen Goodman

¹⁸² Jonathan Herring and Jo Bridgeman do so. Herring, *supra* note 99; J. Bridgeman, "Children with Severe Disabilities and their Families: Re-Examining Private Responsibilities and Public Obligations from a Caring Perspective" in M. Freeman ed, *Law and Bioethics. Current Legal Issues*, vol 11 (Oxford: Oxford University Press Scholarship, 2008) online: <<http://www.oxfordscholarship.com/view/10.1093/acprof:oso/9780199545520.001.0001/acprof-9780199545520-chapter-19>> [Bridgeman, "Children with Severe Disabilities"]; and J. Bridgeman, "Caring for Children with Severe Disabilities: Boundaried and Relational Rights" in M. Freeman & D.A. Freeman eds, *Children's Health and Children's Rights* (Leiden: Nijhoff, 2005) 99 [Bridgeman, "Caring for Children"]. As does Kiran Manhas in "Sufficiency of Home Care for Extraordinary Children: Gender and Health Law in Canada" in J. Bridgeman, H. Keating & C. Lind eds, *Regulating family responsibilities* (Burlington, VT: Ashgate, 2011) 279 [Manhas, "Sufficiency of Home Care"].

¹⁸³ Herring, *supra* note 99 at 1. There is literature in the area of critical administrative law, some of which touches down on litigation involving mothers with disabled children and which I address in subsequent chapters.

provides a discussion of the effects of forced custody relinquishment in exchange for state-supported caregiving services in America.¹⁸⁴ She asserts that the practice causes trauma to the child and to the parents “since it separates the sick child from the family that cannot afford treatment.”¹⁸⁵ Goodman refers to this practice as being “a nationwide problem.”¹⁸⁶

In Canada, this issue has been explored in the grey literature, for example by the Office of the Ontario Ombudsman¹⁸⁷ and in local¹⁸⁸ and national¹⁸⁹ newspaper coverage, as well as by British Columbia’s Pivot Legal Society.¹⁹⁰

In Anglo-American liberalist culture, people are perceived as individuals separate from one another.¹⁹¹ Our legal rights are predicated upon the concept of an autonomous individual capable of realizing her rights individually. As feminist legal scholars discuss, autonomy has not been envisioned in a manner fitting most women’s lives. Autonomy has been extended to children in rights discourses, with scholars noting that in the United Nations *Convention on the Rights of the Child*, child interests have shifted from protection to choice. Children’s interests are now conceived as separate¹⁹² from those of their mothers.

The work of feminist theorists assists in the conceptualization of problems caregiving mothers experience with being unable to realize their legal rights to support. One of these is political theorist, Jennifer Nedelsky. She challenges the standard meaning of autonomy, which is characterized by individual rights and boundaries. She asserts that one can learn about autonomy not from the lone man’s existence, but based on the requirements of childcare.¹⁹³ Nedelsky reconfigures autonomy as a maternal construct, asserting that autonomy should be considered in terms of the interactions in which it evolves.

¹⁸⁴ Gwen Goodman, “Accessing Mental Health Care for Children: Relinquishing Custody to Save the Child” (2003-2004) 67 Alta L Rev 301 at 303. She comments that several states have statutes that prohibit this practice. However, she also notes many states continue to follow the practice and adds that many institutions will not provide treatment without this legal step having been taken, *ibid* at 304. There are several articles on the issue in the US literature.

¹⁸⁵ *Ibid* at 306.

¹⁸⁶ *Ibid* at 304.

¹⁸⁷ Office of Ontario Ombudsman, *Children with special needs: Between a Rock and a Hard Place. Parents Forced to Place their Children with Severe Disabilities in the Custody of Children’s Aid Societies to Obtain Necessary Care* (Toronto: Ombudsman Ontario, 2005) online: <<http://www.ombudsman.on.ca/Investigations/SORT-Investigations/Completed/Children-with-special-needs---em-Between-a-Rock-an.aspx>> [Ontario Ombudsman, *Between a Rock and a Hardplace*].

¹⁸⁸ See Page, *supra* note 18.

¹⁸⁹ See Karen Howlett, “Ontario Minister’s Departure Leaves Disabled Kids in Limbo” *The Globe and Mail* (4 July 2005) A5.

¹⁹⁰ Darcie Bennett & Lobat Sadrehashemi, “Broken Promises: Parents Speak about B.C.’s Child Welfare System” (Vancouver: Pivot Legal Society, 2008) online: <http://d3n8a8pro7vnm.cloudfront.net/pivotlegal/legacy_url/310/BrokenPromises.pdf?134576564>.

¹⁹¹ Jennifer Nedelsky, *Law’s Relations: A Relational Theory of Law Autonomy, and Self* (Oxford: Oxford University Press, 2011) at 125 [Nedelsky, *Law’s Relations*].

¹⁹² Bruce C. Hafen & Jonathan O. Hafen, “Abandoning Children to the Autonomy: The United Nations Convention on the Rights of the Child” (1996) 37 Harv Intl LJ 449 at 450. They state “separate from their parents.”

¹⁹³ Nedelsky, *Law’s Relations*, *supra* note 191 at 125.

She views autonomy instead as a *capacity* that can be developed or lost. Her version of autonomy is found in relationships, which ought to be supported. Stating that the collective is constitutive of individuals, Nedelsky argues that “law, rights and the state bear a large responsibility for constituting relations”¹⁹⁴ and as such, legal obligations should attach to them. In the same discussion, she comments further that individual rights approaches undermine autonomy, providing the example of disputes in the area of social assistance.¹⁹⁵ Such a reconceptualization would have implications for mothers’ legal rights to support, which presently are limited to possible statutory claims and applications for determination of eligibility for benefits. However, Nedelsky’s relational version of autonomy is not the one upon which Canadian law is based. In Canada, there is a legal expectation that even isolated, sole support caregiving mothers should (be able to) achieve liberal autonomy.

Nedelsky’s ideas help one to understand what the cases I examine show, which is that many mothers fail to become ‘autonomous’ and require state support. The law is one problem. Policy is another. Nedelsky explains that when policy is gendered, policymakers “remain ignorant of key dimensions of human life,” and lack the experience and knowledge to govern effectively.¹⁹⁶ Policymakers appear to be unaware about detailed care realities for severely disabled children, in spite of an abundance of explanatory literature.¹⁹⁷

In a similar vein, Martha Fineman argues that policy development ought to focus on what appropriate expectations of the family should be, especially in light of poverty.¹⁹⁸ Fineman asserts that there is a collective responsibility for dependency, both of the child and of what she has coined as being the ‘derivative dependency of the caregiver.’ This derivative dependency is evidenced in Chapter Six and Seven, where caregiving mothers struggle to access needed monetary supports through provisions for their disabled children. Fineman argues that justice demands a robust obligation towards those who provide care. Her suggestion resonates in the setting of mothers of disabled children, where mothers perform the ‘work’ of caring, often in an extraordinary way.¹⁹⁹ Fineman reminds us that it is common for

¹⁹⁴ Nedelsky, *Law’s Relations*, *supra* note 191 at 75.

¹⁹⁵ *Ibid*

¹⁹⁶ Jennifer Nedelsky, “New Norms of Work and Care: Re-Thinking What It Means to Be a Responsible Adult” (Paper delivered at the Conférence Jennifer Nedelsky at the Université de Lausanne, 17 June 2014) [unpublished, archived online: <http://biencanada.ca/congress/wp-content/uploads/2014/06/BIEN2014_Nedelsky.pdf> at 4 [Nedelsky, “New Norms of Work”].

¹⁹⁷ George et al studied this in relation to raising a child with a chronic illness. Ajesh George et al “Working and Caring for a Child with Chronic Illness: Barriers in Achieving Work-Family Balance” (2008) 14:1 Journal of Management and Organization 59 at 60. In examining support policy, one queries what decision makers have read to educate themselves about such matters.

¹⁹⁸ Martha A. Fineman, “Cracking the Foundational Myths: Independence, Autonomy, and Self-Sufficiency” (2000) 8:1 Am U J Gender Soc Pol’y & L 13 at 27 [Fineman, “Foundational Myths”].

¹⁹⁹ Kiran Manhas, & Ian & Mitchell, “Extremes, Uncertainty and Responsibility across Boundaries: Facets and Challenges of the experience of Transition to Complex Pediatric Home Care” (2012) 16:3 Journal of Child Health Care 2 [Manhas & Mitchell, “Extremes, Uncertainty and Responsibility”].

family caregivers to be uncompensated, as well as unrecognized,²⁰⁰ and Canadian reports support her observation.²⁰¹ She argues that the gendered nature of (the assumed) family is crucial to the maintenance of the “foundational myths of individual independence, autonomy, and self-sufficiency.”²⁰² I tackle these and other myths as they relate to law that constrains caregiving mothers in subsequent chapters.

Fineman suggests that assuming a particular family formation in public policy is problematic, and I note that this is especially true where disability is concerned. Examining policy for disabled children in Ontario, the assumed family for provincial policymakers does not appear to include a severely disabled child, the single-parent family, disabled mothers and so on. It is still concerned with the policy needs of the normative nuclear family, which is premised upon male support.

At the same time, Canada has become a country that characterizes responsibility for the care of dependent individuals as primarily one of ‘the family’, which ultimately translates into the responsibility of women. This is done such that male responsibility for children “has been rendered invisible.”²⁰³ There have been different responses to the predicament mothers and disabled children find themselves in. Burton et al. made suggestions arising out of their research for support to mothers with severely disabled children, such as workplace accommodations and caregiver allowances.²⁰⁴ Fineman, on the other hand, has proposed a collective responsibility approach to support.²⁰⁵ However, as legal scholars like Nedelsky note, a collective approach does not ‘fit’ with liberal legal tenets such as individualism and autonomy. Nor does the increasing privatization of care into the hands of mothers and private, largely female childcare workers fit with a collective approach.²⁰⁶

Characterizing care as quintessentially a private act remains strongly reflected in Canadian support policy.²⁰⁷ This is the backdrop to the barriers Canadian mothers with disabled children face when seeking support. Societal representations interact, such that the combination of the expectation of autonomy in mothers and difficulties inherent in the realization of the private support obligation, in fact, translate into sole-support caregiving mothers struggling for unattainable or inadequate private support.

200 “Foundational Myths”, *supra* note 198 at 14.

201 See Interview of Suzana Pekrul in Kathy Tomlinson in “B.C. Cuts Respite for Family of Severely Disabled Child”, CBC News British Columbia (May 13 2008) online: CBC <<http://www.cbc.ca/news/canada/british-columbia/story/2008/05/12/bc-norespite.html>>.

202 Fineman, “Foundation Myths”, *supra* note 189 at 14.

203 See Shelley AM. Gavigan & Dorothy E. Chunn, “From Mothers’ Allowance to Mothers Need Not Apply: Canadian Welfare Law as Liberal and Neo-Liberal Reforms” (2007) 45:4 Osgoode Hall Law School 733 at 737, 771.

204 Peter Burton & Shelley Phipps, “Economic Costs of Caring for Children with Disabilities in Canada” (2009) 35:3 Canadian Public Policy 269 at 280.

205 “Foundational Myths”, *supra* note 198 at 18.

206 See Bridgeman, “Children with Severe Disabilities”, *supra* note 182, discussing parental responsibility throughout her chapter.

207 In *A.L. v Ontario (Minister of Community and Social Services)* (2006) 83 OR (3d) 512, 274 DLR (4th) 431 (ONCA) [*A.L.* (2006) cited to OR], Mr. Justice Sharpe made a point of stating the matter of care for children with severe disabilities is a private one.

At the time when welfare reform was in full swing, feminist political theorists like Nedelsky, Minow, and Shanley (among others) advanced a relational theory of rights to address problems women have with support in law. These scholars engaged with welfare reform in their writing about power, politics and the family.²⁰⁸ Martha Minow also worked in legal clinics and advocated for marginalized clients. For example, they reviewed American constitutional law cases that dealt with family law issues, noting that rights discourses do not always agree as to which rights are relevant and which ought to prevail.

Martha Minow and Mary Lyndon Shanley advance a theory of rights which conceive of the individual as separate, and yet also as being situated in a nexus of relationships involving care and dependency and, importantly, attachments.²⁰⁹ They ask what it is that people owe one another as family members and as citizens. They posit that rights to financial support and care ought to arise from relationships of varying ranges of intimacy, and would focus attention on claims arising from interdependence.²¹⁰ Not limiting their discussion to private law, Minow and Shanley consider such themes as whether government has obligations to ensure the health and welfare of children, and raise the issue of social change in the area of medical technology as requiring new thought in the areas of respite and disability care.²¹¹ They further discuss whether an individual rights-based discourse would ever be an adequate basis on which to found a legal theory of the family.

Minow and Shanley thus raise the issue of interdependence, which is a significant feature of maternally complex care. The dependency of severely disabled children on their mothers for intimate and health-related needs and their extraordinary requirements for care, make it is apparent that the ‘individual’ articulation of legal rights advanced in law cannot account for support of such complex care. Indeed, Britain’s Jo Bridgeman states that a relational approach to rights best captures the situation where there are children with significant disabilities.²¹²

Canadian law professor Jennifer Llewellyn examined legal rights as expressed in *Auton*²¹³ and *Chaoulli*,²¹⁴ arguing that the Supreme Court of Canada’s employment of the liberal, individualist concept

²⁰⁸ Feminists were involved in the debates about welfare reform, those I mention, but others too, chose to examine the impacts of reforms on the economic survival of poor mothers and their poor children. See for example Martha Minow. “The Welfare of Single Mothers and their Children” (1994). Connecticut Law Review 26, 817.

²⁰⁹ Martha Minow & Mary Lyndon Shanley, “Relational Rights and Responsibilities: Revisioning the Family in Liberal Political Theory and Law” (1996) 11:1 Hypatia 4 at 19.

²¹⁰ *Ibid* at 24. Their observations imply that the present conceptualization of legal rights in families is inconsistent with what actually takes places inside families.

²¹¹ *Ibid* at 17.

²¹² Bridgeman, “Children with Severe Disabilities”, *supra* note 182 at 218. Thus, feminist legal literature from the UK, the US and Canada promotes relational consideration of rights.

²¹³ *Auton (Guardian ad litem of) v British Columbia (AG)*, 2004 SCC 78, [2004] 3 SCR 657.

²¹⁴ *Chaoulli v Quebec (AG)*, 2005 SCC 35, [2005] 1 SCR 791. This case involved a challenge to the prohibition on private health insurance in Quebec. There was a s 7 challenge with respect to lengthy wait lists.

of rights has led to an inability to properly respond to claims in healthcare. She argues that this is because Canadian courts have failed to appreciate the relational features inherent in s 7 and s 15 of the *Charter*, a failure which has resulted in difficulty in arriving at just decisions.²¹⁵ Llewellyn's insights have implications for my project, particularly since part of what caregiving mothers provide is healthcare. Again claims brought by mothers in chapters six and seven reveal difficulties with caregiving mothers' ability to access supports that are legally framed in statutes and policy as for the individual, rather than support for care.

The Status of Caregiving Mothers

In critiquing motherhood, labels are important. Chamallas,²¹⁶ like Fraser and Gordon,²¹⁷ states that words used to describe mothering reveal cultural norms. Phrases seen in past and present law and policy such as 'single mother,' 'welfare mother,' 'working mother,'²¹⁸ 'unfit mother' and 'unwed mother,'²¹⁹ solo mothers who get a "free-ride",²²⁰ contain normative information. Yet there is no term to describe 'caregiving mothers', although the care they perform is itself characterized in society as benevolent.²²¹ Words control and stigmatize mothers whose children do not meet societal expectations for good mothers.²²² Words also reveal status. Legal theorist Dorothy Roberts writes that features of the political institution of motherhood subordinate women. She points to society giving women the "enormous responsibility of child rearing" and states that it is "the status of child-bearer that is determinative of a

²¹⁵ Jennifer Llewellyn, "A Healthy Conception of Rights?: Thinking Relationally About Rights in a Health Care Context", in Jocelyn Downie & Elaine Gibson eds, *Health Law at the Supreme Court of Canada* (Toronto: Irwin Law, 2007) 57 at 59.

²¹⁶ M. Chamallas, *Introduction to Feminist Legal Theory*, (Gathersburg, MD: Aspen Law and Business, 1999) [Chamallas, *Feminist Legal Theory*].

²¹⁷ Nancy Fraser & Linda Gordon, "'Dependency' Demystified: Inscriptions of Power in a Keyword of the Welfare State" (1994) 1:1 *Social Politics* 4.

²¹⁸ Chamallas, *Feminist Legal Theory*, *supra* note 216.

²¹⁹ Dorothy Roberts, "Racism and Patriarchy in the Meaning of Motherhood" (1993) 1:1 *Am U J Gender Soc Pol'y & L* 1 [Roberts, "Racism and Patriarchy"].

²²⁰ Nedelsky claims there is a connection between women and their rights which has to do with devaluing the work they do and she quotes Nancy Fraser as stating that 'free-riders' are men who avoid providing care and doing domestic work, rather than "poor solo mothers who shirk employment" in Jennifer Nedelsky, "The Gendered Division of Household Labor: An Issue of Constitutional Rights" in Beverley Baines, Daphne Barak-Erez & Tsvi Kahana eds, *Feminist Constitutionalism: Global Perspectives* (New York: Cambridge University Press, 2012) 15 at 25; Nancy Fraser "After the Family Wage: Gender Equity and the Welfare State" (1995). 22:4 *Political Theory*, 591 at 25.

²²¹ See Rosemarie Garland-Thomson, "Benevolent Maternalism and Physically Dis-abled Figures: Dilemmas in Stowe, Davis and Phelps" (1996) 68:3 *American Literature* 555 at 566. Garland-Thomson points out that some feminist theorists, including, Ruddick and Gilligan, "associate feminine socialization more with an ethic of care than with rights and autonomy" *Ibid* at 580.

²²² See Roberts, "Racism and Patriarchy", *supra* note 219 at 5, 12 n 60, discusses the notion of good versus bad mothers and how these characterizations are brought about in the context of race.

woman's identity" adding that the work mothers do is degraded and unremunerated."²²³ She discusses words used historically to devalue black mothers in particular and adds that the word 'motherhood' in America describes a white institution.²²⁴

Terms such as those above reflect status misrecognition of mothers who fall outside the idealized version of motherhood. The literature describes "drug addicts" who were poor, black, pregnant women and mothers found by the child welfare and the criminal justice systems to be guilty of fetal harm and drug use respectively. I suggest here that they were also judged for 'imposing' the 'burden' of care for their (believed to be) disabled infants on the state, whom the mothers alone are responsabilized for bringing into the world.²²⁵ These vulnerable mothers' own disability as addicts is moreover framed as crime.²²⁶ Interacting statuses placed these women on the extreme margins of motherhood. All the while, predictions about "crack babies" have apparently not been borne out. One researcher found "nothing to back up predictions that cocaine-exposed babies were doomed for life," stating, "[w]hen you have a myth, it tends to linger for a long time."²²⁷

This provides an example of how economically-marginalized and/or racialized mothers have been treated by the state at the intersection of poverty and *possibly* disabled children. Such attitudes introduce false notions of maternal choice and impose maternal responsibility for disability. At one time, law was concerned with women being caused a fright, as a belief was held that a fright could be responsible for the birth of a disabled infant.²²⁸ In this much older legal 'concern', mothers were not always responsabilized for causing a child's disability. Philip Ferguson's explanation however accords with the statement above which is that between 1820 and 1910 the economically marginalized were 'morally blamed' for most childhood disability, "especially those with the bad judgement to be both poor and female."²²⁹ He states from 1920 to 1980 the belief held was that disabled children harmed families.²³⁰ The subsequent shifts he

²²³ *Ibid* at 5.

²²⁴ *Ibid* Roberts at 15 (journal of Gender and the Law)

²²⁵ See Dorothy Roberts, "Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy" (1991) 104:7 Har L Rev 1419. Roberts does not use a disability rights lens, rather she uses feminist, legal, and critical race analyses.

²²⁶ Approximately 120,000 addicted mothers, with minor children are reported to be imprisoned in the United States. 11.4 % of African American children have a parent in jail as a result of the War on Drugs. See Collateral Costs: Incarcerations Effects on Economic Mobility. The PEW Charitable Trusts, at 18.

http://www.pewtrusts.org/~media/legacy/uploadedfiles/pcs_assets/2010/collateralcosts1pdf.pdf

²²⁷ Susan FitzGerald, "Crack Baby Study Ends with Unexpected Result", *The Inquirer* (22 July 2013) online: <http://articles.philly.com/2013-07-22/news/40709969_1_hallam-hurt-so-called-crack-babies-funded-study>.

²²⁸ Chamallas and Kerber address the 1901 case of *Dulieu v White and Sons* (1901), 2 KB 669, in which a pregnant plaintiff alleged that her experience of emotional shock caused her to give birth prematurely to an "idiot" baby. Martha Chamallas & Linda K. Kerber. "Women, Mothers and the Law of Fright: A History" (1990) 88:4 Michigan Law Review, 814 at 830.

²²⁹ Philip M. Ferguson. "A Place in the Family: An Historical Interpretation of Research on Parental Reactions to Having a Child With a Disability" (2002) 30:3 The Journal of Special Education, 124, at 124.

²³⁰ *Ibid* at 125.

describes are the neurotic parent, the dysfunctional parent and the suffering parent. He ends with what he states is the least seen approach to child disability, which is that of *the powerless parent*. This approach arose from parent narratives, referencing scholarship from the 1970s and 1980s. He states that the focus more recently has been on the adaptive family.²³¹ This approach poses other kinds of problems for caregiving mothers, which I discuss in my thesis.

According to Adrienne Rich, motherhood denies women the ability to fully actualize themselves,²³² although not all mothers would agree. In this project, the presence of a disabled child is seen to provide an opportunity for self-actualization by some mothers, but not necessarily in a chosen manner. Related to this, Carpenter and Austin use metaphors of text and margin to interpret the experiences of mothers with children with ADHD. Their observations have relevance to the framework I employ in examining support law. They explain that the text of the patriarchal motherhood myth is occupied by the good mothers and that beyond the text, is the margin. It is in the margin that the children with ADHD and their mothers are situated by society. The authors explain that “mothers measure poorly if their children are outside the text.”²³³ The boundaries of the text are carefully policed by involved others who judge the value of mothers as being lower when they and their children are situated outside the text.²³⁴ These authors state that mothers do not passively sit in the margins, and their mothering is seen to mess up the margins, in particular when they trouble the margins.²³⁵ Carpenter and Austin claim that troubling the borders of the motherhood myth is ‘work.’ They also claim that this work is effortful, consequential and disabling, something that requires careful strategy.²³⁶ Their study found that mothers outside the text felt the impacts of being silenced, criticized and hurt, but also states mothers found ways to manage that. They also state that in struggling to find a place within the text of motherhood, some mothers had complex experiences from which they were able to critique the text.²³⁷ In other words, they problematized the content of the text. However they found that the mothers who troubled the margins in order to be included in the text actually reinscribed the mythology of motherhood that placed them outside-of-the-text of the myth. These metaphors of text and margin can be applied to mothers with severely disabled children who seek support in law. For example, as I later discuss, there are example of support provisions for women that have been crafted for mothers in the text and as such exclude mothers in the margins.

²³¹ *Ibid* at 127

²³² Adrienne Rich, *Of Woman Born: Experience and Institution* (New York: Norton, 1995) at 42 [Rich, *Of Woman Born*].

²³³ Carpenter & Austin, *supra* note 96 at 662.

²³⁴ *Ibid*, at 662

²³⁵ Carpenter & Austin *supra* note 96 at 662

²³⁶ *Ibid* at 671.

²³⁷ *Ibid* at 670

Literature dealing with the status of mothers provides important context for arguments made regarding the right to support. Generally, oppression has been described as taking form socially through processes of marginalization, stigmatization, exclusion and isolation.²³⁸ It takes shape in experiences of the devaluation of a mother's self and the devaluation of her child(ren).²³⁹ Forms of oppression "such as racism, classism, sexism, heterosexism, ageism, disablism (sic) are interlocked", being described as socially-constructed power imbalances and ideologies benefitting one group at the expense of others.²⁴⁰

Where mothers care for disabled children, Home states that their oppression is hidden. She points to the "denial of a group's right to full participation in society, through undervaluing the group and limiting its access to power and resources."²⁴¹ This denial has been described as a failure in inclusion by the disability rights community,²⁴² and has been described as emblematic of status misrecognition by feminist political theorist Nancy Fraser.²⁴³

Status misrecognition of caregiving mothers has relevance to their ongoing low visibility in laws that affect them and to their weak positioning in relation to laws they seek to challenge. Indeed, as seen in Roberts' work, at the intersection of race, disability, and motherhood, law itself deals with mothers oppressively.

Status misrecognition manifests in various ways; one is through the unspoken discourse of the failed mother. This has relevance because of what this discourse brings to law. Linda Blum asserts that mother-blame "serves as a metaphor for a range of political fears," arguing that "[w]hile all mothers are potentially unfit, mothers raising children with disabilities pose an important deviant case" because they defy simple classification.²⁴⁴ This may also explain some of the difficulties inherent in including them in

²³⁸ However also through violence, exploitation and powerlessness, See for example Iris Marion Young "Five Faces of Oppression" in *Oppression, Privilege, & Resistance* edited by Lisa Heldke and Peg O'Connor Boston: McGraw Hill 2004).

²³⁹ *Ibid.*

²⁴⁰ Children's Aid Society of Toronto, *Anti-Oppression, Anti-Racism Policy*, (Toronto: CAST, 2006) online: <<http://www.torontocas.ca/wp-content/uploads/2009/castaoarpolicyrevisedfeb132009.doc>> at 4, "Oppressions such as racism, classism, sexism, heterosexism, agism, disableism etc., are interrelated and *interlocked* (Dei, 1996). That is to say, aspects of social differences such as race, gender, sexual orientation and class are unintelligible without considering them in relation to each other (Ng, 1993)."

²⁴¹ Alice Home, "Challenging Hidden Oppression: Mothers Caring for Children with Disabilities" online (2002) 3:1 *Critical Social Work* <<http://www1.uwindsor.ca/criticalsocialwork/challenging-hidden-oppression-mothers-caring-for-children-with-disabilities>>.

²⁴² The denial of inclusion has been dealt with in litigation. See for example The Supreme Court of Canada, *Eaton v Brant County Board of Education*, [1997] 1 SCR 241, 31 OR (3d) 574; and *Moore v British Columbia (Education)*, 2012 SCC 61, [2012] 3 SCR 360 [Moore].

²⁴³ "Feminist Politics", *supra* note ## at 31. Fraser refers to institutionalized patterns of cultural value regulated through interaction based on androcentric norms that serve as impediments to women's parity.

²⁴⁴ Linda M. Blum, "*Mother-Blame in the Prozac Nation: Raising Kids with Invisible Disabilities* (2007) 21:2 *Gender & Society* 202 at 203.

support legislation.²⁴⁵ Other literature is informative also. The lack of interest in, and at times even disdain, regarding caregiving mothers' needs that characterizes mainstream critical disability studies forms an ironic thread in negative discourses concerning mothers.

Janice McLaughlin's work confirms that "the reticence to debate the significance of care has created a lack of engagement with and even hostility towards parents of children with disabilities."²⁴⁶ Her insight regarding negative consideration runs counter to state representations of caregiving mothers as noble, a feature I address in Chapter Four.

Clearly there is both complexity and difficulty in how mothers with disabled children are perceived. Notably, Lewiecki-Wilson and Cellio have observed that "the figure of the mother is overdetermined and vexed for both feminism and disability studies."²⁴⁷ They add, "[m]others have often been blamed for their children's impairments or perceived impairments; the figure of the mother is closely linked to cultural scripts of care and dependency," noting that "the role of nondisabled parents (and perhaps especially, of mothers) within disability rights movements and disability activism remains controversial."²⁴⁸

Being marked by complex controversy is not conducive to easily understood and accepted claims to support. On the contrary, it undermines such claims at various turns, in ways that are difficult to counter.

Another side of this is that disabled mothers with disabled children ought to be less vexed in some of these contexts, but paradoxically they are not. For example, within disability studies there has been a relative silence on the matter of disabled mothers with disabled children, which is one reason why Hansen and Turnbull's article, "Disability and Care: Still Not 'Getting It'" is so important.²⁴⁹ Cultural scripts of the kind these authors refer to are reflected in how law deals with mothers with disabled children. Or as Hansen and Turnbull show, fails to do so. The fact of disabled mothers of disabled children being controversial contributes at least in part to their rights to support remaining elusive. This is not the only obstacle that gets in the way of mothers accessing supports for disabled children and themselves, however.

²⁴⁵ The family law case *BGF v DMF*, 2012 ABQB 698 [*BGF*], discussed in Chapter Seven, offers an example of children who may defy classification in that area of law. When that occurs, proving need becomes very difficult.

²⁴⁶ Janice McLaughlin, "Conceptualizing Intensive Caring Activities: The Changing Lives of Families with Young Disabled Children", online: (2006) 11:1 Sociological Research at para 1.2 <<http://www.socresonline.org.uk/11/1/mclaughlin.html>>.

²⁴⁷ Cynthia Lewiecki-Wilson & Jen Cellio eds, *Disability and Mothering: Liminal Spaces of Embodied Knowledge* (Syracuse: Syracuse University Press, 2011) at 3.

²⁴⁸ Alison Kafer, "More than reproduction", Book Review of *Disability and mothering: Liminal spaces of embodied knowledge* by Cynthia Lewiecki-Wilson & Jen Cellio eds, (2012) 32:4 Disability Studies Q at para 1.

²⁴⁹ Nancy Hansen & Lorna Turnbull, "Disability and Care: Still Not 'Getting It'" (2013) 25:1 CJWL 116.

To the limited extent that the mainstream of the Canadian disability rights movement has taken an interest in children, it has often advocated for the child in isolation.²⁵⁰ In Sobsey's early work, for example, the role and needs of mothers are aggressively overlooked.²⁵¹ At the same time, as Cockburn points out in *Children and the Feminist Ethic of Care*, rights-based approaches are adversarial: rights compete and one set of rights may trump another set of rights.²⁵²

In disability rights, disabled children's rights have trumped those of their caregiving mothers, a phenomenon I examine at length in Chapter Seven. It makes no sense to pit the rights of a severely disabled child against those of a mother when it is *maternal-disabled, child-oriented* support under discussion.

Cockburn²⁵³ and Garland-Thomson²⁵⁴ point out that until recently, disability research focused on the caregiver and that "the critical or radical perspectives of disability politics countered this trend."²⁵⁵ Critical disability politics had in mind the medical model disability research concerning care provided to disabled people in institutions.²⁵⁶ Mother-caregivers have been seen not to matter in the critical disability discourses, whose theorists have done the very thing they complain of, which is the failure to recognize. Discounting caregiving mothers and adding to their status misrecognition makes no sense in the context of disability in childhood, even if to do so may confer some sort of advantage on disability status.²⁵⁷

Saetersdal argues that while acknowledging the problems with the previous era's improper "fixation on crisis and misery" was important, the idealization of parenting disabled children that followed invited another oppressive ideology. The danger, she argues, is that this new orientation will herald "dominating political and theoretical trends" that will suppress the perspectives of those struggling, especially in an era of cutbacks.²⁵⁸ Her point, made in 1997, turns out to be correct. Knight would agree,

²⁵⁰ The Roeher Institute at York University did not do this to the same extent in their literature, as evidenced in L'Institute Roeher Institute, *Beyond the Limits* (North York, ON: Author, 2000). This document reports on interviews with 50 mothers.

²⁵¹ Scorgie & Sobsey, *supra* note 160; Dick Sobsey, "Why We Shouldn't Blame the Murders of Disabled Kids on Lousy Services" *Not Dead Yet* (2 March 2001) online: <<http://www.notdeadyet.org/why-we-shouldnt-blame-the-murders-of-disabled-kids-on-lousy-services>>.

²⁵² Tom Cockburn, "*Children and the Feminist Ethic of Care*" (2005) 12:1 *Childhood* 71.

²⁵³ *Ibid* at 80.

²⁵⁴ Rosemarie Garland-Thomson, "Integrating Disability, Transforming Feminist Theory" (2002) 14:3 *NWSA Journal* 1 at 16 [Garland-Thomson, "Integrating Disability"]. She states that a disability perspective nuances feminist ethics of care by considering the power relations between those who give and those who receive care.

²⁵⁵ Cockburn, *supra* note 549 at 80.

²⁵⁶ One of those whom Cockburn references is Jenny Morris. *Ibid* at 80. Morris J. (ed.) (1996) *Encounters with Strangers: Feminism and Disability*. London: The Women's Press.

²⁵⁷ For example, in promoting the view of disabled persons as both autonomous and independent. Children however are neither of these things, whether disabled or not.

²⁵⁸ Barbro Saetersdal, "Forbidden Suffering: The Pollyanna Syndrome of the Disabled and Their Families" (1997) 36:1 *Family Process* 431 at 432.

recently stating that mothers of disabled children must “project the identity” of the good mother,²⁵⁹ and further commenting that they “occupy a problematic and transgressive social space.”²⁶⁰

This literature suggests that the support needs of such mothers troubles and threatens critical disability theory. Such theory, to the extent that it discounts caregiving mothers’ roles in the lives of disabled people, may actually contribute to the invisibility of mothers in disability discourses, discourses that are crucial to social, and therefore legal, change.

Meanwhile, important political conversations continue to exclude mothers, allowing for the omission of the costs mothers incur when they assume complex care.²⁶¹ Disability advocacy groups are called upon to consult with government, but to the extent that mothers are not central to such consultations, their interests are not represented. Indeed, the contested space caregiving mothers occupy is demonstrated in disability theory itself. Garland-Thomson asserts “a feminist disability study complicates both the feminist ethic of care and liberal feminism in regard to the politics of care and dependency.”²⁶² Some feminist-oriented critical disability work manages to conflate the rights of women who care for disabled children with their children’s rights, undermining rights to support. If mothers break down and can no longer provide care, then the disabled child is at risk of institutionalization, the very thing that disability rights fought against. Cockburn references Anita Silvers as also stating that the care provided by caregivers of disabled people is valorized socially over disabled people themselves.²⁶³ These approaches serve the ends of critical disability theory perhaps, which is to advance autonomy, but they do not serve severely disabled children whose autonomy is tied to their relationship with their mothers.

Mothers with disabled children face difficulty in other quarters as well. For example, the goals of ameliorating child poverty have been pursued separately from maternal poverty.²⁶⁴ As well, Dobrowolsky

²⁵⁹ Kathryn Knight, “The Changing Face of the ‘Good Mother’: Trends in Research into Families with a Child with Intellectual Disability, and Some Concerns” (2013) 28:5 *Disability & Society* 660 at 666.

²⁶⁰ *Ibid* at 661.

²⁶¹ See Ruth Lister, “Children (but not Women) First: New Labour, Child Welfare and Gender” (2006) 26:2 *Critical Social Policy* 315 [Lister, “Children First”]; and Wanda Wiegers, “The Framing of Poverty as ‘Child Poverty’ and Its Implications for Women” (Ottawa: Status of Women Canada, 2002) online: <http://www.rwmc.uoguelph.ca/cms/documents/78/Wiegers_1-128.pdf>. I discuss this issue below.

²⁶² “Integrating Disability”, *supra* note 254 at 16.

²⁶³ Cockburn, *supra* note 549 at 80, refers to Anita Silvers (as does Garland-Thomson, “Integrating Disability”, *supra* note 254 at 16) for her position that ethics of care threaten an even more oppressive paternalism. However, severely disabled children do not eschew their mother’s care. In my project, it is not the case that care threatens disabled children, *but rather the lack of it*. Silvers’s perspective makes sense in the adult context, where adults with disabilities are often given even less voice than those who provide them with supports. Anita Silvers, “Reconciling Equality to Difference: Caring (f)or Justice for People with Disabilities” (2009) 10:1 *Hypatia* 30

²⁶⁴ As discussed in numerous scholarly works, see e.g. Wiegers, *supra* note 261; Janine Brodie & Isabella Bakker, *Where Are the Women: Gender, Equity, Budgets and Canadian Public Policy* (Ottawa: Canadian Centre for Policy Alternatives, 2008) online: CCPA <http://www.policyalternatives.ca/sites/default/files/uploads/publications/National_OfficePubs/2008/Where_Are_the_Women_Contents_Intro.pdf>; Lister, “Children First”, *supra* note 261; Alexandra Z. Dobrowolsky & Jane

asserts that rhetoric may not match up with realities for children.²⁶⁵ Her observation resonates in discussions concerning disabled children.²⁶⁶ A *child* focus in poverty advocacy has been best described as having “effectively struck women’s full citizenship from the political agenda.”²⁶⁷

Policy practice that separates mothers and children is troubling where disability is concerned. As noted above, Martha Fineman describes how families are portrayed in policy, stating that myths govern what constitutes a normal family. Confronting myths is likewise central in an examination of the legal right to support of mothers with disabled children, a domain dominated by interweaving myths. Fineman characterizes myths as masking familial realities.²⁶⁸ Where there are children with severe disabilities, the literature suggests that these myths are bigger, the masking greater. For example, a central assumption of the normative family is that children grow up and become independent.²⁶⁹ This harks back to the issue of classic autonomy, itself, I argue, a normative concept. The assumption of child independence is not reflective of the reality today, including for many non-disabled children. Yet it remains an assumption in support policy. The actual circumstances of mothers with disabled children thus escape policy attention.

In reality, there is great diversity in Canadian families. Wanda Weiger’s work ties in with Fineman’s observations. She argues that single, lesbian, racialized, and working-class mothers are constructed as bad mothers because in their differences they have deviated from the idealized family form,²⁷⁰ or to use Fineman’s characterization, they have formed the non-normative family.²⁷¹ This characterization also accords with what Roberts suggests: that where black motherhood is less valued, it reflects an overall “disregard for black humanity.”²⁷² Thus women mothering children, who fail to accord with society’s roles for its children, are deemed deviant for falling short of the ideal.²⁷³

Disabled children and their mothers are part of the diversity Weiger and Fineman refer to. However, rather than perceived as “bad”, as noted caregiving mothers are largely perceived as failed

Jenson, “Shifting Representations of Citizenship: Canadian Politics of ‘Women’ and ‘Children’” (2004) 11:2 Social Politics 154.

²⁶⁵ Alexandra Z. Dobrowolsky, “Rhetoric Versus Reality: The Figure of the Child and New Labour’s Strategic ‘Social Investment State’” (2002) 69 Studies in Political Economy 43 at 57. The rhetoric may sound like an interest in social justice she states, but this may hide goals of regulation and coercion.

²⁶⁶ For example, the rhetoric of future self-sufficiency. See “New Autism Centre Aims to Help with Self-Sufficiency”, *CTV News* (24 November 2011) online: CTV News <<http://toronto.ctvnews.ca/new-autism-centre-aims-to-help-with-self-sufficiency-1.730591>>.

²⁶⁷ Dobrowolsky & Jenson, *supra* note 561 at 173.

²⁶⁸ Fineman, “Foundational Myths”, *supra* note 198 at 14. It is masked by the assumed family. Freire referred to myths as central to oppression.

²⁶⁹ “Growing up” is a culturally laden expression, and independence is too, even in the normative family. The children of wealthy families experience independence and expectations of it differently than do those of poor families.

²⁷⁰ Wiegers, *supra* note 261 at viii.

²⁷¹ Martha Albertson Fineman, *The Neutered Mother: The Sexual Family and Other Twentieth Century Tragedies* (New York: Routledge, 1995) [Fineman, *The Neutered Mother*].

²⁷² Roberts, “Racism and Patriarchy”, *supra* note 219 at 11.

²⁷³ Blum, *supra* note 244 at 203.

mothers in the mainstream and also in disability discourses. What this has to do with politics is, as Blum posits, that neo-liberal restructuring may place disabled children “below the threshold deemed worthy of social investment, leaving even middle-class mothers scrambling.”²⁷⁴ Today, the non-normative family includes a caregiving mother and her severely disabled child, where the child may not be perceived politically as being “the best indicator of the capacity” for Canada’s “economy tomorrow” where that is being measured by “the quality of our children today”, to quote and borrow from Lister.²⁷⁵ This raises the question, how can rights claims be made for this dyad?

Overall, the literature reveals that mothers’ claims to support have not been well-received. Claims brought by mothers have been described by the state as having been brought by ‘militants.’²⁷⁶ Resisting this imagery, there has been a responsive adversarial positioning by mothers. For example, the characterization of the “warrior-mother”²⁷⁷ is part of a newer cultural construction of identity embraced and advanced by mothers of disabled children. The characterization suggests the state of consciousness of some mothers in the context of low levels of public support for family care, along with disability and gender discrimination, as well as these mothers’ unwillingness to accept the way that the state represents both care and them.²⁷⁸ Mothers themselves state that their situations call on them to be ‘fierce’.²⁷⁹ The term warrior-mother also reflects a dual character in a culture that defines the ideal mother not as a combatant, but as a nurturer.

Litigating mothers are situated in a particular context. It is one in which they provide forms of care at the behest of the privatizing state and also themselves. The refutation to the allegation that they care as a matter of choice would be that the desperate responses of caregiving mothers to state strategies,

²⁷⁴ Blum, *supra* note 244 at 222.

²⁷⁵ Ruth Lister, “Investing in the Citizen-Workers of the Future: Transformations in Citizenship and the State under New Labour” (2003) 37:5 *Social Policy and Administration* 427 at 430 [Lister, “Citizen-Workers”], quoting from Catherine Haddon, *Making Policy in Opposition: The Commission on Social Justice, 1992-1994* (London: Institute for Government, 2012).

²⁷⁶ In the case of autism in Québec, see Carole Senechal, Normand Giroux, & Jacques Forget, “Les recours judiciaires personnes autistes pour la reconnaissance de leurs droits dans des services socio-sanitaires et d’éducation au Québec et au Canada” (2004) 15:2 *Revue Francophone de la Déficience Intellectuelle* 217 at 218.

²⁷⁷ Something I learned at a talk by Patricia Douglas entitled “Mothering and Autism: Rethinking the Limits of the Human” (Delivered at the Munk School of Global Affairs, 29 January 2014) [unpublished]. “Autism Mothers” is another term now seen in media, such as Jenny McCarthy, *Warrior Mothers: A Nation of Parents Healing Autism against All Odds* (Boston: Dutton, 2008). In a Facebook communication dated January 18, 2015 Douglas mentioned that Polly Tommey, a high-profile UK autism advocate and mother, uses the term. Polly Tommey also uses the term, “Autismum”. This suggests to me that some mothers are taking on their child’s disability as part of their own identity, and wearing it, as it were, into the political arena.

²⁷⁸ This corresponds with ideas in Mustakova-Possardt, *Study of Morality*, *supra* note 145 at 6, respecting moral motivation and resilience seen in those who have arrived at a critically conscious understanding.

²⁷⁹ I refer here to Emily Rapp’s 2013 memoir. Emily Rapp, *Still Point in a Turning World* (New York: Penguin Books, 2013) at 95.

such as litigation, legal abandonment and at times, suicide and filicide, indicate a lack of choice.²⁸⁰ To understand how such “choices” came to be, one needs to grasp what has happened to mothers politically.

Privatization, Mothers and Severely Disabled Children

Having now examined some perspectives on rights and caregiving mothers, I have set the stage for my discussion of privatization of care, both scholarly areas that inform my later arguments concerning the right to support. It is essential to grasp the meaning of privatization in order to understand gaps in support to mothers.²⁸¹

Privatization is a political approach that relies on the market to allocate resources, with proponents believing it to be efficient. Under it, social welfare and other similar state supports are seen as primarily the responsibility of families and charities. There is no or minimal obligation perceived that the state ensures in the support of its citizens.²⁸² This latter feature is a launching point for discussing the intersection of privatization and gender. Central to note is that the state’s privatizing projects rely heavily on women taking up former state obligations to support/care. This was made possible because of a range of social role expectations on women already in place, but also, I argue, due to a remarkable expansion of healthcare performance expectations on mothers. Roberts,²⁸³ referencing McKinnon, states that motherhood features heavily in women’s ‘subordination’ overall, and one can see how this is particularly true in the setting of children with considerable complex care needs.

The process of privatization of state care for severely disabled children was built on social expectations already in place.²⁸⁴ Roberts goes so far as to state that mothering is a defining aspect of how gender is socially structured and agrees with Fineman that patriarchy is the defining ideology constructing

²⁸⁰ There is no legal language to discuss the issues I raise. Lucinda Finley addresses this problem in her work, *supra* note 58 at 886. She explains this problem as women not having shaped legal definitions and terms and the impacts of that. Language entrenches thinking and this includes legal language, *ibid* at 887. Legal language she argues shapes, constrains, confines, our understandings of how law affects women, *ibid* at 891. What may be seen as “choice” in law is actually the performance of preservative features commonly inherent to mothering.

²⁸¹ See Joan Gilmour, “Creeping Privatization in Health Care: Implications for Women as the State Redraws Its Role” in Barbara Cossman & Judy Fudge eds, *Privatization, Law and the Challenge to Feminism* (Toronto: University of Toronto Press, 2002) 267. Vickers & Paris, *supra* note 190 at 93, address western states’ “escalating pushes” of care for dependents on to family, with women having been socialized into care roles with no regard to their own health or financial wellbeing. This corresponds with Nancy Fraser’s description, in “Feminism, Capitalism and the Cunning of History” (Lecture delivered at the French Sociological Association, Paris, 21 July 2009) online: Dailymotion, <http://www.dailymotion.com/video/x9xdr8_feminism-capitalism-and-the-cunning_news>, of capitalism as ‘cunning’ where it cooperates with the human rights movement to deinstitutionalize children with severe disabilities.

²⁸² See Judy Fudge & Brenda Cossman, *Introduction* in Cossman & Fudge, *supra* note 281, 1 at 3.

²⁸³ Roberts, “Racism and Patriarchy”, *supra* note 219 at 3 n 6, referencing Catharine A. McKinnon, *Feminism Unmodified* (Cambridge, MA: Harvard University Press, 1987).

²⁸⁴ Such policies did not claim they were extending motherhood but rather putting care back where it naturally belongs, inside ‘families’.

motherhood.²⁸⁵ So, as other literature suggests, is ableism.²⁸⁶ Under privatization, mother's (unarticulated) rights are trodden on by the state. There is literature fleshing out the ways in which privatized care policies in combination with deinstitutionalization and social role expectations on women negatively impacted mothers' autonomy.²⁸⁷ Indeed, Katherine Vatri Boydell described deinstitutionalization as being a women's issue.²⁸⁸ The result has been that many mothers with disabled children have not been able to do things that others may choose to do as a matter of course, including work. Some caregiving mothers accuse both government and feminism of leaving them behind.²⁸⁹ As discussed below, this reality is reflected in the words chosen by the state to describe policies that now responsibilize complex care within 'families'.²⁹⁰

Rowbotham links language and women's consciousness. She states that language conveys power, dominance, and control and has the power to silence those who are subordinate.²⁹¹ Chamallas,²⁹² as well as Fraser and Gordon,²⁹³ note that language connotes whose responsibility it is to perform care. The major programs that provide support in Ontario are called *Assistance for Children with Severe Disabilities* (ACSD), and the *Family Responsibility Act*. There is also the *Ontario Disability Support Program Act*.²⁹⁴ ODSP states that families and individuals are also responsible for disabled adults' support. Respite services in Ontario were made available through "Special Services at Home". Bold, assuming words like 'special,' 'assistance,' 'family responsibility' and 'home' make clear where obligations to support lie.

²⁸⁵ Roberts, "Racism and Patriarchy", *supra* note 219 at 3. However, Roberts states that racism must be added as heavily influencing that ideology. *Ibid*, at 23 n 124.

²⁸⁶ This idea comes across in the interviews of mothers in Sara Ryan & Katherine Runswick-Cole, "Repositioning Mothers: Mothers, Disabled Children and Disability Studies (2009) 23:3 Disability & Society 199.

²⁸⁷ See e.g. Nancy M. Yantzi, Mark W. Rosenberg & Patricia T. McKeever, "Getting Out of the House: the Challenges Mothers Face when their Children Have Long-Term Care Needs" (2007) 15:1 Health Social Care Community 45; and Nicole M. Yantzi & Mark W. Rosenberg, "The Contested Meanings of Home for Women Caring for Children with Long-Term Needs in Canada" (2008) 15:3 Gender, Place & Culture 302.

²⁸⁸ She states that most adults in treatment for serious conditions were living at home at the time of writing her dissertation. Katherine Vatri Boydell, *Mothering Adult Children with Schizophrenia: The Hidden Realities of Caring* (Doctoral Thesis, York University, Department of Sociology, 1996) [unpublished] at 27.

²⁸⁹ The connection between lack of care supports and ability of mothers to work is addressed below in depth. See Sue Robbins, "The Ones Left Behind. How do our governments and workplaces support, or fail to support, those of us who care for vulnerable children?", *Huffington Post* (21 December 2016) online: <http://www.huffingtonpost.com/entry/the-ones-they-left-behind_us_585b479ce4b014e7c72eda33>.

²⁹⁰ One need only look to statutes providing disability supports. Alberta's *Family Support for Children with Disabilities Act*, Chapter F-5.3, s 3, (also known as *Samantha's Law*) sets out that province's Family Support Services.

²⁹¹ Rowbotham, *supra* note 127 at 32.

²⁹² Chamallas, *Feminist Legal Theory*, *supra* note 241 at 290, examines words used to describe single mothers receiving social assistance. Single mothers on social assistance are lone-carers semantically constructed as dependents by the state.

²⁹³ Fraser & Gordon, *supra* note 217 at 21, discuss "the semantics of dependency."

²⁹⁴ *Family Responsibility Act*, RSO 1990, c F.3 (as opposed to the *Father's Responsibility Act*). See also the preamble to the *Ontario Disability Support Program Act*, SO 1997, c 25 [ODSPA]. The ACSD program is for children rather than being framed as assistance for mothers with severely disabled children.

Crittenden too writes that institutions define motherhood, and that ideologies are responsible for giving it form. Ideology is expressed, in part, through language. Issues understood to contribute to mothers' inequality are greater in the setting of disability in childhood. Crittenden, for example, provides an informative discussion of the employment situation of a mother with a graduate degree in special education. She had cared full-time for a severely disabled child for 13 years. Crittenden describes how the mother was instructed by an employment counselor to leave her caregiving experience out of her resume and in job interviews.²⁹⁵

Linguistic features thus facilitate status misrecognition of caregiving mothers. This has links to the law, as language interpretation is a feature of support litigation. In support law, words may limit, delineate, mislead, render vague, and frame. Words may be challenged however, including with outcomes that undermine the goals of equality for mothers under the *Charter*. In 1986, poor single mothers with "illegitimate" children in Nova Scotia who were benefit recipients under provincial family support policy found themselves unsupported as a result of a *Charter* challenge to the use of language in legislation specifically targeted and tailored to support them.²⁹⁶ This older example shows the degree to which language plays a role for caregiving mothers, in particular, in maintaining support. I return to other similar examples in Chapter Six.²⁹⁷

There is something distinctly difficult about the ability to realize the right to support of mothers *per se*. Perhaps as figures heavily weighed down by myth in our cultural imagination, it remains difficult for mothers to be seen as legal subjects, even where law has been enacted for them.

The ability and ease with which the state has implemented privatizing policies in the face of community opposition also raises questions about mothers' legal rights.²⁹⁸ In *Mothering in Law: Defending Mother's Rights*, Day asserts that feminists have not taken up the defense of the legal rights of mothers and suggests that feminists have perceived mothering as the project of social conservatives.²⁹⁹ However, Hallstein argues that issues concerning the institution of motherhood have "come out of the

²⁹⁵ Ann Crittenden, *The Price of Motherhood: Why the Most Important Job in the World is Still the Least Valued* (New York: Metropolitan Books, 2010) at 3.

²⁹⁶ *Phillips v Nova Scotia (Social Assistance Appeal Board)* [1986] DLR (4th) 633, 76 NSR (2d) 240 (NSSC) [*Phillips* cited to DLR]. In *Phillips*, a single father with 'a child born out of wedlock', who had been awarded custody and who was unemployed was denied benefits when he applied for them under the *Family Benefits Act*, SNS, 1977, c 8. Section 5(4) of the statute provided that "Subject to this Act and regulations, a mother whose dependent child was born out of wedlock is eligible to apply for benefits on her own behalf and on behalf of her dependent child." (First unnumbered section of the case). He initially brought a judicial review procedure, by way of an application for certiorari to quash the administrative decision denying him family benefits. The Social Assistance Appeal Board upheld that decision, however the lower court dismissed the application to quash the administrative decision, finding instead that s 5(4) of the *Act* infringed s 15(1) of the *Charter*.

²⁹⁷ In Chapter Six, I discuss Joyce Dassonville's Nova Scotia litigation, where one can also see the role language plays in barring mothers from their legal rights to support.

²⁹⁸ For example, by opposition by Miriam Edelman, and others.

²⁹⁹ Day, *supra* note 26 at 1, states "social conservatives claim the turf of motherhood."

closet for many feminist contemporary writers,”³⁰⁰ although she is not addressing legal rights to support, as is Day. Hallstein suggests that motherhood poses problems for feminist thought,³⁰¹ something to which Day also alludes in the introductory paragraph of her paper, when she says that all women are affected by how mothers are perceived and treated.³⁰² Day points out that mothers are never only mothers, and notes that, “[w]omen need freedom from family, as well as freedom to family. Only when that is a fully realizable choice, without economic or social penalty, will women be liberated. We are not there yet.”³⁰³ Likewise, women need freedom to provide care and freedom from providing care. The latter requires the realization of rights and state support. We are not there yet either.

Since Day’s paper, other feminist legal scholars, for example Nedelsky³⁰⁴ and Cossman, have expressed concerns about the status of mothers in Canadian society. Cossman asks to what extent we are in the midst of evolving “new cultural norm[s] of mothering” such as the idealization of the stay-at-home mother as a signifier of status and whether such norms are even possible for single, working-class or poor mothers.³⁰⁵ This question is interesting in light of severely disabled children presenting as a unique and little understood subset population within childhood.³⁰⁶ It is also interesting because it draws attention to class, an important under-examined feature in the privatization of care. There is a poor meshing of new mothering norms as described by Cossman³⁰⁷ and this newer subset within childhood described in the health literature, which clearly contributes to a weakening of the legal rights of caregiving mothers. This is especially so for mothers who are not well-off or, who are not well. Mothering norms deal with normative children, and not those children who require complex care.³⁰⁸

³⁰⁰ D. Lynn O’Brien Hallstein, “Conceiving Intensive Mothering” (2006) 8:1-2 *Journal of Research on Mothering* 96 at 96.

³⁰¹ She nicely argues that a feminist analysis of maternity is still needed, since presently theory is split between second wave gains and lingering patriarchal forms. *Ibid* at 105. Sue Robbin’s piece, *supra* note ##, suggested that feminism left caregiving mothers behind.

³⁰² Day, *supra* 26 at 1

³⁰³ *Ibid*. Day also states that, feminists have strongly defended women’s right not to be forced to become mothers. Thus, posing difficulty for disability rights theory, legal theory, and feminist theory.

³⁰⁴ Jennifer Nedelsky, “Reflections on Mothering” (2006) *Nexus* 32, online: U of T Law, <http://www.law.utoronto.ca/documents/alumni/Nexus_06summer.pdf> [Nedelsky, “Reflections on Mothering”].

³⁰⁵ Brenda Cossman, “The ‘Opt Out’ Revolution and Changing Narratives of Motherhood”, *Nexus* (Spring/Summer 2006) 29, online: U of T Law, <http://www.law.utoronto.ca/documents/alumni/Nexus_06summer.pdf> at 30 [Cossman, “Opt Out”].

³⁰⁶ See S. Kirk, “Families’ Experiences of Caring at Home for a Technology-Dependent Child: A Review of the Literature” (1998) 24:2 *Child Care Health and Development* 101 at 101. Kirk asks the question as a subheading, “Who are technology-dependent children?”

³⁰⁷ Cossman refers to new mothering norms as elusive for women who cannot meet them, such as poor women. Cossman, “Opt Out”, *supra* note 305. Nedelsky writes about the norms of professional life making demands on professional mothers as oppressive. Nedelsky, “Reflections on Mothering”, *supra* note 304. Obviously in the setting of a severely disabled child, whether the mother is single or not, such norms are all the more oppressive, as the case law I examine reveals to be the case.

³⁰⁸ Although beyond scope, mothering norms are also class-bound.

‘Intensive mothering’ is the term used to describe care of typical children today. This requires that care involve large amounts of maternal attention and time.³⁰⁹ Care norms for the typical child are thus understood to be demanding.

Mothers of disabled children also engage in intensive mothering, but with additional health care and disability support features. Currently, mothers who perform both typical intensive³¹⁰ and maternally complex care who leave the labour market to care for their children are understood to have done so as a matter of personal/private ‘choice’.³¹¹ Caregiving mothers’ reasons for departure from the workforce vary, but lack of appropriate and affordable childcare is certainly one of them.³¹² Cossman states that there are costs to mothers for ‘opting out’ of the workforce, seen to be the result of choice.³¹³ She argues that this issue needs to be examined so that legal rights in the area of family law are not weakened. Cossman’s insight applies to other areas of law, and includes those pertaining to my project.

Privatization of care for working mothers in the setting of typical children has been described as a double shift. The situation for those providing complex care is dire, and Manhas observes that society is happy to have caregiving mothers “do all the heavy lifting.”³¹⁴ Extending the ‘opting-out’ explanation attributed to mothers of non-disabled children to mothers with disabled children will further hide the fact that many mothers with severely disabled children have no such choice,³¹⁵ since the privatizing state has tasked them with numerous forms of care. Legal cases I address in Chapters Four, Six, and Seven reveal that mothers are also expected to carry over time, the economic, social and physical risks associated with complex care.³¹⁶

³⁰⁹ Hallstein, *supra* note 300 at 97, referencing Sharon Hays, *The Cultural Contradictions of Motherhood* (New Haven: Yale University Press, 1996).

³¹⁰ Mothering also where there are children with medically complex care needs requiring “extraordinariness” as described in Manhas & Mitchell “Extremes, Uncertainty and Responsibility”, *supra* note 199.

³¹¹ Naomi Breslau, David Salkever & Kathleen S. Staruch. “Women’s Labour Force Activity and Responsibility for Disabled Dependents: A study of families with disabled children” (1982) 23:2 J Health and Social Behaviours 169. Moreover, as this article found, different family formations are affected differently.

³¹² Ordinary childcare is still largely a private matter in Canada. This has recently been raised as a human rights concern. See Kendra Milne, *High Stakes: The Impacts of Child Care on the Human Rights of Women and Children* (Vancouver: West Coast Leaf, 2016) online: <<http://www.westcoastleaf.org/2016/07/12/high-stakes-impacts-child-care-human-rights-women-children/>>.

³¹³ Cossman, *supra* note 305 at 30. See also, Sue Robbins, *supra* note 289.

³¹⁴ Manhas, “Sufficiency of Home Care”, *supra* note 182 at 297.

³¹⁵ See Janet Read, “There Was Never Really Any Choice: The Experience of Mothers of Disabled Children in the United Kingdom” (1991) 14:6 Women’s Studies International Forum 561. Read describes the carework mothers with disabled children do as exacting and describes the nature of restrictions they encounter as caregiving mothers.

³¹⁶ The case involving Cynthia Harris, reviewed below is one amongst many. Other forms of silencing take place where disabled children and their mothers are struggling with violence. Thus, physical costs are silenced. Stacey Clifford Simpican coined the term complex dependency to describe extreme violence of a very small number of disabled persons with autism towards their mothers. Stacey Clifford Simpican, “Care, Dependency, and Violence: Theorizing Complex Dependency in Eva Kittay and Judith Butler” (2015) 30:1 Hypatia 219 at 222, 224. I make this comment reluctantly as to my knowledge the vast majority of autistic individuals are not remotely violent, whereas

The silencing of maternal challenges is “part of a broader pattern of isolation and privatization”.³¹⁷ This is reflected in employment policy, which affects all mothers, with the impact on mothers with disabled children being especially harsh, as case law discussed later shows. Cain comments that current approaches “denigrate ‘love’s labour’ and caring relations even as they demand them in order to operate profitably”.³¹⁸ Overall, the literature on developments in normative mothering provides useful information in considerations of non-normative, maternally complex care.

It can be seen from the literature that mothering does not take place in a political vacuum.³¹⁹ Yet, classic critical theorists have ignored the specific economic, social and political positioning of mothers.³²⁰ Nancy Fraser critiques problems that the capitalist welfare state poses for mothers’ status. She claims that the location of women is problematic in this arrangement because their roles and interests as mothers, citizens and as workers are ‘in conflict’ with the structure and workings of the state itself.³²¹ Fraser’s insight here is invaluable. It helps one to understand why support-seeking mothers face challenges asserting legal claims for support or in the alternative “fitting in” to paid work. If they are supported neither as carers nor as workers, it might be surmised *they are outside* the general scheme of legal life. Currently, legal and political decisions concerning the support of mothers of disabled children are made within available options in the neo-liberal state. This is a state described by Sawyer as the right-wing, liberal, capitalist state and as the ‘night watchman’ or ‘minimalist’ state.³²² According to Sawyer, the minimalist state emphasizes self-reliant citizens,³²³ therefore not recognizing the support needs of caregiving mothers with severely disabled children. Sawyer describes this state formation as being a male construct, asserting “the image of the citizen is an essentially self-contained individual rather than the social liberal/feminist view of the individual caught up in a web of interdependence within the

many non-autistic people can be. However, where they do act out, the results can be catastrophic, as in the case of Angie and Robert Robertson, which I address later.

³¹⁷ Nedelsky, “Reflections on Mothering”, *supra* note 304 at 33.

³¹⁸ Ruth Cain, “The Court of Motherhood: Affect, Alienation and Redefinitions of Responsible Parenting” in Bridgeman, Keating & Lind, *supra* note 182, 67 at 84.

³¹⁹ See Wiegers, *supra* note 261; Fraser, “Talking about Needs”, *supra* note 4; Nancy Fraser, “Women, Welfare and the Politics of Need Interpretation” (1989) 2:1 *Hypatia* 103 [Fraser, “Need Interpretation”].

³²⁰ Fraser asserts for example that Jürgen Habermas failed to account for gender altogether. Which is not to say that his theory cannot be applied to mothers with severely disabled children, as Patricia McKeever did in her 1991 Dissertation, entitled *Mothering Chronically-Ill Technology Dependent Children: An Analysis Using Critical Theory*. (Doctoral Dissertation, York University, 1991) [unpublished, archived at Database dissertations and theses@york].

³²¹ Nancy Fraser, “What’s Critical about Critical Theory? The Case of Habermas and Gender” (1985) 35 *New German Critique* 97 [Fraser, “What’s Critical”]. A similar criticism has been leveled at Freire. It is also to be noted that Marx also failed to properly account for care. The lack of critical theory about care is all the more reason why standpoint theory at this point in time makes sense.

³²² Marian Sawyer, “Gender, Metaphor and the State” (1996) 52 *Feminist Rev* 118 at 120.

³²³ *Ibid* at 121.

community.”³²⁴ Sawyer states that the neo-liberal concepts of ‘self-reliance’ and ‘independence’ hide “relations of dependency and interdependency within the family.”³²⁵ Sawyer refers to the state rendering of care as invisible as “a vanishing trick”, whereby mothers implicitly lack the characteristics of citizens.³²⁶ In this sense, her comments also underscore the source of caregiving mothers’ misrecognition. Later, I explore the issue of caregiving mothers’ lack of full citizenship status in relation to unmet private support obligations for disabled children.

Looking closer into the politics of neo-liberalism, Kendra Coulter points out that it was not just an economic agenda, and was not only an ideology. She describes it as comprising a multi-pronged strategy that restructured culture, institutions, and economic processes.³²⁷ In addition, she states that neo-liberalism was an economic, political and moral doctrine that centered the individual as the basis for society. Flowing from the focus on individualism was the goal of having consumption be the source of individual identity and means to participation. Under neo-liberalism, according to Coulter, one is identified as a tax-payer and as a service-user. This accords with the aim of creating optimal conditions for the market place and for capital. In addition to privatization through selling off state assets, governments de list services from public provision. Coulter adds that it includes user fees, and private-public collaboration in investment, and lauds volunteerism and fundraising in the stead of public investment.³²⁸ Of particular relevance to my project is that there is a significant emphasis on a highly decontextualized push for individual responsibility and choice. Coulter points out that inequities in power and economic status between genders are ignored.³²⁹

Political scientists debate whether neo-liberalism is actually gone or whether it has been modified. Some scholars assert that neo-liberalism has given way to the ideals of the social investment state³³⁰ (also referred to as the Third Way Approach). The neo-liberalism of the 1970’s did change in the 1990’s, when social justice and social inclusion issues were “added” to political agendas.³³¹ However these items added had investment rationales to support their retention. As such scholars have described the Third Way as neo-liberalism in disguise.³³²

³²⁴ *Ibid* at 122, referencing Ruth Lister, “Women, Economic Independence and Citizenship” (1990) 19:4 J Social Policy 445.

³²⁵ Sawyer, *supra* note 322 at 122.

³²⁶ Sawyer *Ibid* note 322 at 122.

³²⁷ Kendra Coulter “Women, Poverty, and the Production of Neo-Liberal Politics in Ontario, Canada” (2009). Journal of Women, Politics and Policy, 30, 23 at 26.

³²⁸ Coulter, *Ibid* at 28.

³²⁹ Coulter *supra* 327 at 28.

³³⁰ Some might argue that any discussion about neo-liberalism is passé. However, its effects are still evident in disability support policies.

³³¹ Coulter *supra* 327 at 28.

³³² Coulter *supra* 327 at 28.

Some political economists assert that social investment state perspectives that are intended to promote investment in human capital and which centre children in its economic policy, devalue children who fail to accord with the state's vision. This would include the severely disabled child. Worthiness relates to a child's projected place in the future economy.³³³ The investment state advances economic agendas that Lister,³³⁴ Jenson³³⁵ and other academics show situate the normative child at their centre, while marginalizing those children who are non-normative, and their mothers, too. The difficulty under neo-liberalism is that the ideology fails to account for caregiving mother's realities, as people whose lives are heavily intertwined with health and other forms of care for non-normative children. The difficulty for these mothers under the Social Investment State is that the children into whom mothers pour all of their time and energy are unlikely to meet the state's objectives of investing in children. Both neo-liberalism and the social investment state ignore people whose lives cannot be lived in keeping with their societal doctrines.

Moreover, investment state strategies are said to eclipse parents' (in my project, mothers') interests. To support this, Lister notes that the British official who launched National Childcare Week declared that "it is important for men to play a real part in raising children for the benefit of children, fathers and society as a whole."³³⁶ He omitted to mention mothers.

The omission of mothers from political discussions about their children is mentioned in diverse critiques. The reasons for this may be complex. In the global economy, it is the individual who is expected to responsibly manage her risks, and to do so with little state support. It is, I believe, unclear even to policymakers whether or not mothers are "individuals," and this is both good and bad. Re-responsibilizing mothers for all forms of care has been seen throughout the West. Australia's Toni Delany claims this agenda is particularly directed at mothers with sick children. In the Canadian context, McKeever described feminine caregiving as a discourse that undergirds expectations of maternal performance of complex care. This approach holds that mothers are the natural and optimal caregivers for children, no matter how severe their disabilities. This assumption is called into question in some of the literature³³⁷ as this results in isolated³³⁸ mothers, tasked with bringing about good outcomes for children

³³³ See Lister, "Children First", *supra* note 261 at 316. She credits Anthony Giddens with the approach, where the state promotes the taking of personal responsibility to make the most of the chances that life offers.

³³⁴ Lister, "Citizen-Workers", *supra* note 275.

³³⁵ Jane Jenson, "Redesigning Citizenship Regimes after Neoliberalism. Moving towards Social Investment" in Nathalie Morel, Bruno Palier & Joakim Palme eds, *What Future for Social Investment?* (Stockholm: Institute for Future Studies Research Report, 2011) 27.

³³⁶ Lister, "Children First", *supra* note 261 at 319. She references Dobrowolsky's, "Rhetoric Versus Reality: The Figure of the Child and New Labour's Strategic 'Social Investment State'", *supra* note 265.

³³⁷ See Peter et al, *supra* note 46 at 1625, who discuss the problems with this assumption.

³³⁸ Donna Thomson describes her and another caregiving mother's isolation. Thomson states that "Being the mother of a child with multiple disabilities is by definition, a very lonely life," *The Four Walls of My Freedom* (Toronto: The House of Anansi, 2013) at 85. She also re-quotes, *ibid* at 86, the words of a mother with a severely disabled

with severe impairments.³³⁹ Breen states that such approaches confuse parental involvement in care with responsibility for that care,³⁴⁰ which is often *health* care, an important point. However, it appears that this ‘confusion’ (or conflation) is deliberate. In this way, the hard blow dealt to mothers in the retraction of care by the state is shielded from plain view.

The approach of responsabilizing mothers for health and other care may seem, to many, to be non-partisan, with elements of both the left and right finding it attractive.³⁴¹ Perhaps this makes sense in light of the fact that governments like to save money and must be accountable on that front. However, the unjust aspect is that spending reductions are at the expense of the vulnerable. Lister discusses New Labour’s approach to ‘citizenship’ stating that under New Labour, there are to be “no rights without responsibilities”, with social justice being arrived at through the market.³⁴² No one has explained how this works in the setting of severely disabled people who are not financially or otherwise independent. Nor has anyone delineated what the outer threshold of responsabilization is, or should be. Based on this approach, caregiving mothers ought to be seen as exemplary citizens; yet they are viewed through a different lens, that of sacrifice in the private sphere. The point here is that for many caregiving mothers, there are significant and onerous responsibilities with few rights, as governments increasingly contend that the care of disabled children, youth and adults is a private matter.³⁴³

child from Hans S. Reinder, *Receiving the Gift of Friendship. Profound Disability, Theological Anthropology and Ethics* (Grand Rapids, Mich: William Eerdmans, 2008), who describes her situation as enforced seclusion and how profoundly that affected her sense of self.

³³⁹ See Delaney, *supra* note 112. Her research revealed that mothers were held accountable for the birth of sick children through medical and public health discourses. Thus responsabilization went beyond care.

³⁴⁰ Lauren J. Breen, “Early Childhood Service Delivery for Families Living with Disabilities: Disabling Families through Problematic Implicit Ideology” (2009) 34:4 *Journal of Early Childhood Education* 14 at 18.

³⁴¹ The terms neo-conservative and neo-liberal do not correspond with liberal or conservative, they are different in their orientations to state supports. The neo-liberal state does not ascribe to a form of citizenship that includes rights to much in the way of state supports and moreover takes any and all routes possible to reprivatize support and care. Self-reliance is one core feature of neo-liberal ideology. See Brenda Cossman, “Family Feuds: Neo-Liberal and Neo-Conservative Visions of the Reprivatization Project”, in Cossman & Fudge eds, *supra* note 281, 169. Cossman observes that ‘welfare’ mothers are seen in this vision as blameworthy for their dependency, *ibid* at 170. Neo-conservatism, in relation to my project, ascribes to an ideology of the family as a basic social unit, *ibid* at 185, and has a specific idea of what that unit ought to look like and its policies are directed towards that social unit. Neo-liberal ideology, in combination with neo-conservative values, has been harmful to single caregiving mothers in particular. Classic liberalism has accounted for the need of a welfare state, in which those in need are supported. Classic conservatism has too, but with different ideas backing it, such as noblesse oblige, rather than legal rights to support.

³⁴² Lister, “Citizen-Workers”, *supra* note 275 at 428-429, referencing the words of Anthony Giddens. His approach links so-called investment in human capital with social policy as opposed to “direct provision of economic maintenance.” She also includes a discussion of the essentializing of children in a political approach that views women’s inequality as now passé political issue, *ibid* at 436.

³⁴³ Kiran Manhas does so in the context of Canadian politics and law in “Sufficiency of Home Care”, *supra* note 182 at 299. In fact, she states that notions of public responsibility prioritize and exploit maternal responsibilities. This is a useful characterization as it juxtaposes not simply private versus public, but maternal versus the state. The responsibility is not merely given to private families; the state specifically targets mothers.

North American scholars have identified gender biases in privatizing policies, which they posit harm women economically.³⁴⁴ Likewise, Britain's Lister comments that "it is 'implausible' to treat decisions as to who cares for children in the family as purely 'private' when the choice is almost always that the mother is going to remain at home. It is a structural problem, and progressive politics has an obligation to fight old-fashioned structures."³⁴⁵

Lister, like Cossman above, describes the way UK politics and policy also treat maternal decisions as being the result of personal choice. She notes that this implies autonomy, something alluded to in her discussion of mother's "choosing" to opt out of the labour market, discussed above.³⁴⁶ The reality is that severe disability poses problems for those who argue in favour of the privatized state. It is not only mothers who have the right to support, but disabled persons, too. However, in Canadian society, where children with disabilities are concerned, it is women who are assigned the role of their care. The law reflects this assignment of care responsibility, thus legal rights to supports are weak, and rights-claims beyond those repeatedly need to be made, as the below chapters show.

Canadian economist Isabella Bakker draws attention to the fact that it is primarily women who are tasked with social provisioning as the state has withdrawn from this domain.³⁴⁷ She refers to this as a 're-privatization' involving changes in "the household, the state and social institutions" and "governance of the basic mechanisms of livelihood."³⁴⁸ Bakker analyzes re-privatization as guided by the view that it puts social reproduction back into its 'natural' place, within the 'family'. This political approach is in keeping with woman's perceived 'natural' role as mothers as described by Rich. For example, there is now the expectation that women will provide home care, once provided by the state,³⁴⁹ and now framed as 'family' care. There is a paradox to consider here. In spite of a history of institutional care for certain kinds of children,³⁵⁰ Canada remains without national daycare. Daycare is a needed institution by women generally, but one that Canadian politicians of all stripes have failed to implement.³⁵¹ It is not that institutional oversight for children *per se* is the issue, after all children are in state-run schools across

³⁴⁴ See discussion in such articles as: Olsen, "Market", *supra* note 134; Susan Boyd, *Challenging the Public/Private Divide: Feminism, Law and Public Policy* (Toronto: University of Toronto Press, 1997); Gilmour, *supra* note 281.

³⁴⁵ Lister, "Children First", *supra* note 261 at 319.

³⁴⁶ *Ibid.*

³⁴⁷ Isabella Bakker, "Social Reproduction and the Constitution of a Gendered Political Economy" (2007) 12:4 New Political Economy 541 at 541.

³⁴⁸ *Ibid* at 545.

³⁴⁹ Dennis Raphael & Toba Bryant, "The Welfare State as a Determinant of Women's Health: Support for Women's Quality of Life in Canada and Four Comparison Nations" (2004) 68 Health Policy, 63 at 72. They relay that the moving of care from hospitals to primarily women has had adverse effects on many, but especially on women.

³⁵⁰ Those people involved in formulating law and policy to institutionalize children in need of support historically have had recourse to boarding schools, where many of their children were raised, as Veronica Strong-Boag points out in *Fostering Nation? Canada Confronts its History of Childhood Disadvantage* (Waterloo: Wilfred Laurier University Press, 2001) at 45 [Strong-Boag, *Fostering Nation?*].

³⁵¹ Childcare has been described as in crisis by experts in the area. See Raphael & Bryant, *supra* note 349 at 70.

Canada. It is *care* that is the point of contention and that needs to be borne in mind throughout this dissertation.

This discussion is complicated by the fact social care, and health care, have been conflated, to government advantage, as I noted.³⁵² Thus, healthcare for severely disabled children has been the past responsibility of the state, provided either through healthcare (hospitals) or public social care (other forms of entrenched institutional care, such as children's and infants homes, orphanages,³⁵³ foster care and large institutions). Therefore, technically one can argue that withdrawal of care to medically disabled children is simply privatization.

With the deinstitutionalization of disabled children in the 1980s and thereafter, the socially conservative value of the essential private-ness of disability care has been bolstered. Yet, the literature shows that it is to the economic detriment of women who bear children and who have inadequate resources to leverage sufficient support to permit them a measure of real autonomy when those children are or become severely disabled. This approach to care genders disability, lowering the status of disabled persons, along with that of caregiving mothers. It also introduces the concept of extreme economic risk to childbearing for women. This risk is tied to low levels of state support and weak enforcement of those few avenues of private support made available through statutes.

Explanations of social provisioning as undertaken less often by the state, and more often in the home, do not relay the full story where mothers with disabled children are concerned. The term, 'social provisioning,' itself inadequately covers the special medical and health care required by these children, in particular, those with medical complexity and/or who are technology-dependent. This is because medical care falls outside the social provisioning that takes place in social reproduction.³⁵⁴

McKeever describes mothers as performing skilled health care for chronically ill and medically disabled children.³⁵⁵ This situation has been described as posing ethical problems.³⁵⁶ There are a range of troubling issues, for example, financial distress when a mother's loss of income takes its toll on her ability to support the family. Murphy notes that there has been a failure to attend to the issue that is the most

³⁵² Daycare and preschools are beyond scope, but noted to be problematic for mothers with disabled children. See discussions in Isabel Killoran, Dorothy Tymon & George Frempong, "Disabilities and Inclusive Practices within Toronto Preschools" (2007) 11:1 Intl J Inclusive Education 80 at 81. Their research found that the many directors of preschools for example stated they would not provide a space to a disabled child, at 93.

³⁵³ Strong-Boag, *Fostering Nation?*, *supra* note 350 at 43.

³⁵⁴ Barbara Cameron states feminist political economists use the term "social reproduction" to describe the recreation of the population across time frames. See, Barbara Cameron, "Social Reproduction and Canadian Federalism" in Kate Bezanson & Meg Luxton eds, *Social Reproduction: Feminist Political Economy Challenges Neo-Liberalism* (Montreal: McGill-Queen's University Press, 2006) 45 at 45.

³⁵⁵ McKeever, *supra* note 320.

³⁵⁶ Peter et al, *supra* note 46; Kiran Manhas & Ian Mitchell, "Children with Complex Care Needs Going Home: The Relevance of Ethical Ideas of Proximity" (2009) 4:16 Paediatrics and Child Health 369 [Manhas & Mitchell, "Going Home"].

powerful predictor of family stress, namely stressful challenging care at home.³⁵⁷ Another concern, identified by Murphy, and also Woodgate et al, is the social isolation and lower participation in society by caregiving mothers.³⁵⁸

There is also a literature contesting the rationale for the reprivatization of home care in the 1990s.³⁵⁹ It also asserts that there are ethical problems with privatization, in addition to noting flawed rationales for it. The view that the market could guide this form of care justly was a political myth contested by mothers in Ontario. In support of my comments regarding the failures of privatized complex health care in particular, a study by Quebec's Carnevale et al. quoted one mother as stating she experienced an "injustice" occurring in the setting of "extraordinary" care provided by her to her medically disabled child.³⁶⁰ This highlights that for some caregiving mothers, rights are implicated. If Bakker intended to have complex forms of care subsumed under her definition of social provisioning, then the fact is that the extraordinary care mothers of severely disabled children perform remains an outlier in terms of its quantity, quality, and impact. In this case, present approaches to 'social' provisioning are all the more troubling because they fail to account for what is essentially health care. Bakker also states "that women are called upon to become 'genderless workers and rational economic actors yet at the same time social supports for reproductive and caring work are being weakened and privatized.'"³⁶¹ Foster care and poorly regulated homes for developmentally disabled individuals can be added to this. Both of these have featured in media and in advocacy as being unsafe for disabled children and youth due to lack of government oversight.

The privatization of disability care carries assumptions concerning maternal capabilities, as well as assumptions about a caregiving mothers' willingness and economic ability to perform care. The literature on the privatization of disability care in Canada, once critically evaluated, is useful in understanding why care breaks down, and children are placed into state care. For example, the policy that

³⁵⁷ Giselle Murphy, "The Technology-Dependent Child at Home: In Whose Best Interests?" (2001) 13:7 Paediatric Nursing at 16. Her research was conducted in Britain.

³⁵⁸ *Ibid* at 15. Roberta Lyn Woodgate, Marie Edwards, Jacqui Ripat, "How Families of Children with Complex Care Needs Participate in Everyday Life" (2012) 75 Social Science & Medicine 1912.

³⁵⁹ See e.g. Glen E. Randall & A. Paul Williams, "Exploring Limits to Market-Based Reform: Managed Competition and Rehabilitation Home Care Services in Ontario" (2006) 62:7 Social Science & Medicine 1594 at 1595-1596. Randall and Williams argue privatization neither improved quality nor reduced costs. There has also been a critique of managed competition in the overall CCAC process. See also Pat Armstrong & Hugh Armstrong, *Women, Privatization and Health Care Reform: The Ontario Case* (Toronto: National Network on Environments and Women's Health, 2006). Aside from noting that privatization of care in Ontario has not served the Community Care Access Centres' (CCAC) primarily female employees and patients well (too few nurses, lack of transparency in decision making, and according to *LS v Community Care Access Centre Perth County*, 2004 CanLII 69793 (ON HSARB) [*LS*], too little accountability) it is clear that essential features that would help to ensure rights to care are missing.

³⁶⁰ Franco A. Carnevale et al, "Daily Living with Distress and Enrichment: The Moral Experience of Families with Ventilator-Assisted Children at Home" (2006) 117:1 Pediatrics e48 at e53 [Carnevale et al, "Daily Living"].

³⁶¹ Bakker *supra* note 347 at 550

stipulates such care should take place “at home” presumes a lot, for example, the presence of paternal and other supports that may or may not actually exist. This, in turn, exposes the “gender division of labour in the care for children with disabilities [as] one mechanism for the reproduction of gender inequality ...”³⁶² Paradoxically, and unwittingly perhaps, the disability rights movement played a role in the push for privatization where disabled children and youth are concerned, under the aegis of deinstitutionalization and community living.³⁶³ Commenting on ideological differences between the Disabled Women’s Network (DAWN) and the Council for Canadians with Disabilities (CCD), Vanhala writes that DAWN viewed CCD as being “very patriarchal” and unaware of discrimination against women where disability was concerned.³⁶⁴ It does not appear from what Vanhala says - that what CCD perceived to be a plausible solution to social exclusion and abuse of disabled people who were financially supported in the public sphere - might oppress women once that support was transferred to the community and to the private sphere.³⁶⁵ An uncalculated risk at the expense of women (a percentage of whom would be disabled, poor, single, or already heavily involved in complex caregiving for dependent others) was taken on trust that state supports for community living arrangements would be both forthcoming and sufficient.³⁶⁶ In hindsight this turned out not to be the case. This left the door wide open for child welfare (re) involvement with disabled children, the very thing disability rights advocates did not want, and

³⁶² This mechanism, they state, is not entirely understood. Philip N. Cohen & Miruna Petrescu-Prahova, “Gendered Living Arrangements among Children with Disabilities” (2006) 68:3 *Journal of Marriage and the Family* 630 at 630.

³⁶³ Lisa Vanhala quotes Joan Meister and Shirley Masunda in the “DAWNING Manual” (1998) (No longer available online, no page referenced) in which one feminist disability rights activist states that there was “a strong current of sexism” in the Canadian arm of the disability rights movement. Lisa Vanhala, “Disability Rights Activist in the Canadian Courts: Legal Mobilization, Equality and Accessibility” (Paper delivered at the Annual Meeting of Canadian Political Science Association, Vancouver Canada, 4-6 June 2008) [unpublished, archived by the Canadian Political Science Association, online: CPSA <http://www.cpsa-acsp.ca/papers-2008/Vanhala.pdf>] at 12. Another point to note is that some members of the community living movement at the time were critical of the resistance of some families to receiving their disabled family members moving home for full time care by the wife or mother, upon deinstitutionalization. Family members were criticized as selfish, when the situation was more complex than that would suggest.

³⁶⁴ *Ibid* at 13. The CCD leadership has not been made up entirely of men, now or in the past, and today DAWN is a member organization.

³⁶⁵ The state failed to provide appropriate care. It housed intellectually and physically disabled children in large prison-like complexes, where abuse was institutionalized. In that era mothers were not expected to perform intensive care for severely medically disabled children. In fact, that population of children usually did not survive their medical and genetic conditions or traumatic accidents. Anecdotally, some mothers are reported to have visited their children at these institutions while others abandoned them. The CBC radio program, Michael Enright, “The Gristle in the Stew”, online: CBC <http://www.cbc.ca/thesundayedition/documentaries/2012/08/12/the-gristle-in-the-stew-1/>, about abuses at the large institution, Huronia, located in Orillia, Ontario was the subject of a class action lawsuit by former disabled children kept there. The lawsuit was settled before trial, with the government making a formal apology for the human rights abuses that occurred.

³⁶⁶ There are reports of sick middle-aged parents having to place their young adult children into nursing homes, in Emergency Rooms, and at Provincial Offices. Amanda Telford, a social worker and Ottawa mother left her 19-year-old youth with the provincial developmental services office in desperation. See Andre Meyer, “Parents of Autistic Children ‘Exasperated’ by Costs” *CBC Canada* (2 May 2013) online: <<http://www.cbc.ca/news/canada/parents-of-autistic-children-exasperated-by-financial-costs-1.1366038>>.

concomitantly, psychological oppression of caregiving mothers, through law, when their disabled children had to be given up to the state to receive adequate care.

The child welfare literature offers insights on privatization as well. Hester Lessard, commenting on Canada's child welfare provisions, asserts that the 'residual model' approach is the naturalization of privatized care of children.³⁶⁷ In earlier times, this approach applied only to 'normal' children.³⁶⁸ Now it applies to all children, something that she states can be mistaken for child equality. Child welfare was historically involved in placing disparately vulnerable children in institutions,³⁶⁹ but is more heavily involved with disabled children than non-disabled children for whom at-home care breaks down at high rates.³⁷⁰ Bridgeman refers to this as "the minimalist approach" which aims to "keep care in the private sphere" and which "articulates public responsibilities towards care as a burden on the state and society".³⁷¹ However, if the state itself perceives care as burdensome, why then is it perceived to be acceptable that women shoulder it alone, as Bridgeman notes caregiving mothers do?³⁷² Bakker points to the trend of "the privatization of previously socialized institutions associated with provisioning social reproduction," and she refers to child welfare agencies as demonstrating but one example of that.³⁷³ Note that the care of severely disabled children by the state has traversed from institutionalization to shared care to hard-to-access or lack of care. The issues in this literature are central to mothers' legal rights to support, particularly where mothers seek to share care obligations imposed by provincial child welfare jurisdictions, but in other areas also.

Privatizing policy approaches in Canada hold that good mothers care for their disabled children at home. When mothers can no longer perform or afford to care for their severely disabled children, their children may be placed in a residential treatment centre, or with "specialized" foster mothers.³⁷⁴ The foster home is recognized by the state for its 'specialness'. Yet, biological mothers who provide the same expertise and care do not benefit from recognition. The child with a severe disability who legally transfers from the charge of a mother to that of the state is a further reflection of the gendered political economy

³⁶⁷ Hester Lessard, "Empire of the Lone Mother: Parental Rights, Child Welfare and State Restructuring" (2001) 39:4 Osgoode Hall LJ 717 at 722.

³⁶⁸ See also Strong-Boag, *Fostering Nation?*, *supra* note 350.

³⁶⁹ See Veronica Strong-Boag, "Children of Adversity: Disabilities and Child Welfare in Canada from the 19th Century to the 21st Century" (2007) 32:4 Journal of Family History 413 [Strong-Boag, "Children of Adversity"].

³⁷⁰ Bruce Uditsky & Anne Hughson, "From Protection to Inclusion" in Karin Melberg Schwier, ed. AACL Connections, vol 1 iss 2, (Edmonton: Alberta Association Community Living, 2008) online: <<http://inclusionalberta.org/clientuploads/documents/Connections%20Spring08.pdf>>, report that in a study on Alberta Family and Social Services, almost 70% of the children in care had disabilities.

³⁷¹ Bridgeman, "Children with Severe Disabilities" *supra* note 182 at 12.

³⁷² *Ibid* at 16.

³⁷³ Bakker, *supra* note 347 at 545.

³⁷⁴ As seen in the case of Samantha Martin in Alberta. See "Alberta Girl, 13, Failed by Foster Care, Inquiry Finds", *CBC News* (19 October 2012) online: *CBC News*, <<http://www.cbc.ca/news/canada/edmonton/story/2012/10/19/edmonton-samantha-martin-fatality-inquiry.html>> [CBC, "Alberta Girl"].

that Bakker describes. Bakker also states that male gender bias is built into public policy and as such, policy is formed “from the perspective of male work and life patterns.”³⁷⁵

Caregiving mothers exceed work ethic expectations, with personal costs, but are not remunerated nor even recognized as workers. Health researchers point out “a social belief” that meeting the needs of children is a parental obligation, a flawed belief in its failure to recognize ‘the special burden of complex medical care’ where there are severely disabled children.³⁷⁶ That social belief is itself reflective of bias. Meanwhile, Manhas asserts that the continued “ideological distinction” of the public and private spheres in the setting of mothers with children with complex care needs exploits mothers across numerous axes, at the same time that it fails to receive legal attention.³⁷⁷

This situation brings us back to the issue of uncertain caregiver status. Caregiving mothers’ economic circumstances are but one axis of their continuing uncertain status. The literature concerning the economics of caring for severely disabled children is not marginal to my thesis. Elsewhere in this dissertation, I employ the metaphor of ‘trapped’ in relation to caregiving mothers and the law, and suggest that this metaphor applies in a similar vein to their situation in relation to economic support.

Continuing with the issue of privatization, it must be considered in the context of women’s already existing realities. In their discussion of “the relentless attack on federal social programs,” Brodie and Bakker reference former Minister of Canadian Heritage and the Status of Women, Beverley Oda, of the Conservative government as stating that her government “does fundamentally believe that all women are equal.”³⁷⁸ This statement raises the question of what the Conservative government meant by the word ‘equal’. As *The Harper Record* policy paper shows, almost 40% of single mothers in Canada in 2004 lived below Statistic Canada’s low-income cut-off, thus formal economic equality has not been achieved. This data is not able to address the specific situation of mothers with severely disabled children, whom Petrenchik points out often struggle financially in Canada.³⁷⁹ Justice L’Heureux-Dubé has commented that the term equality is “notoriously indeterminate”,³⁸⁰ however the term does appear in the *Charter of*

³⁷⁵ Bakker, *supra* note 346 at 546.

³⁷⁶ Peter et al, *supra* note 46 at 1625.

³⁷⁷ She examined the issue in terms of mothers’ interests, as opposed to those of ill-defined ‘parents’ or ‘families’. Manhas, “Sufficiency of Home-Care”, *supra* note 182 at 296.

³⁷⁸ Brodie & Bakker, *supra* note 264 at 6. In 2006 when she was Heritage Minister of Canadian Heritage, which included the status of women. See Teresa Healy ed, *The Harper Record* (Ottawa: Canadian Centre for Policy Alternatives, 2008) online:

<http://www.policyalternatives.ca/sites/default/files/uploads/publications/National_Office_Pubs/2008/HarperRecord/Womens_Equality_and_Human_Rights.pdf> at 329.

³⁷⁹ Theresa M. Petrenchik, “Childhood disability in the context of poverty: A discussion paper prepared for the Ontario Ministry of Children and Youth Service” (Hamilton, ON: CanChild Centre for Childhood Disability Research, 2008) online: CanChild

<http://www.canchild.ca/en/ourresearch/resources/ChildhoodDisabilityintheContextofPoverty_CanChild.pdf>.

³⁸⁰ Claire L’Heureux Dubé, “It Takes a Vision: The Constitutionalization of Equality in Canada (2002) 14:2 Yale JL & Feminism at 363.

Rights and Freedoms under s 15(1).³⁸¹ In *Generation Rx: Mothering Kids with Invisible Disabilities in an Age of Inequality*, Blum draws attention to the inequality experienced.³⁸²

The economic inequality that results from an inability of caregiving mothers to work outside the home and have support for care creates problems. For example, remaining at home to perform care for technology-dependent or medically fragile children has been shown to have negative health impacts on mothers.³⁸³ A Canadian report cited by Carly Weeks revealed that mothers who care for disabled children are sick more often than mothers who do not.³⁸⁴ A caregiving mother's need to take time off to recover from illness impacts employment prospects, particularly if illness becomes chronic, should the opportunity arise for them to re-enter the labour market. This is further evidence of gender inequality, and also has legal ramifications. Re-privatization of maternally complex care has imposed human costs beyond the economic ones that are most obvious to government. It is overall inequality that more often accords with complex care.³⁸⁵ In fact, (former) Minister Oda's comment spoke more to the liberal notion of autonomy than it did to substantive equality. Perhaps Oda meant to say that women are now fundamentally autonomous, although that, too, is problematic.

A space has opened up for politicians to assert that the mothers of disabled children are poor because of choices they have made, of their own volition. This may especially be the case where politicians seek to make an economic argument that it is individuals and families, and not the state, who are obligated to protect themselves and their families against risk and "provide for their own futures."³⁸⁶ Arguably this stands in some tension with the social investment state. However, according to Coulter the rhetorical claims made in the Third Way to care about seniors, children and the vulnerable, future

³⁸¹ *Ibid* at 373. It has a legal meaning, and moreover should be interpreted in light of the principle of substantive equality, and not formal equality. Madam Justice Dubé states that the principle of substantive equality requires courts and legislators to consider women's experiences where "they have been ignored or excluded in the course of the law's development."

³⁸² See Masauso Chirwa, Book Review of *Generation Rx: Mothering Kids with Invisible Disabilities in an Age of Inequality* by Linda M. Blum, (2015) Vol. Early View, *Sociology of Health and Illness* 1. Chirwa draws attention to Blum's references to onerous burdens of care and a stingy economy of gratitude for mother's vigilante efforts with their invisibly disabled children.

³⁸³ See e.g. Kai-Wei Katherine Wang & Allan Barnard, "Technology dependent children and their families" (2004) 45:1 *Journal of Advanced Nursing* 36, writing in Australia; Joyce Neuss, *Mothers as Primary Caregivers for their Technology Dependent Children at Home: A Qualitative Study* (Doctoral Thesis of Philosophy, New York University School of Social Work, 2004) [unpublished] writing in the US; and Karen Spalding & P McKeever, "Mothers' Experiences Caring for Children who Require a Gastrostomy Tube" (1998) 13:4 *Journal of Pediatric Nursing* 234, in Canada.

³⁸⁴ Carly Weeks, "Moms of Sick Kids More Likely to Report Being Ill", *Victoria Times Colonist* (22 November 2006) online: *Times Colonist* <<http://www2.canada.com/victoriatimescolonist/news/story.html?id=a85c2596-3cf2-43f9-8f85-c11139e78a35>>.

³⁸⁵ See Petrenchik, *supra* note 379. See also Marcia K. Meyers, Henry E. Brady & Eva Y. Seto, *Expensive Children in Poor Families: The Intersection of Childhood Disability and Welfare* (San Francisco: Public Policy Institute of California, 2000) online: PPIC <http://www.pplic.org/content/pubs/report/R_1000MMR.pdf>.

³⁸⁶ Amber Gazso & Susan A. McDaniel "The Risks of Being a Lone Mother on Income Support in Canada and the U.S.A" (2010) 30:7/8 *International Journal of Sociology and Social Policy* 368 at 370.

generations, our neighbours, and the environment.³⁸⁷ Coulter describes polite receipt of reports about such groups, with little policy change taking place.³⁸⁸

As will be seen, the notion of personal choice is frequently raised in legal cases challenging a caregiving mother's right to support. The 'personal choice' argument has its uses, as it frees government from the harmful consequences of privatization. Gazso and McDaniel point out that under neo-liberalism, the ideology that informs much of the disability policy under discussion here, "risks" are understood increasingly to be self-made, and furthermore "entrench individual responsibility."³⁸⁹

As noted by Gilmour and Bakker respectively, Canada has been experiencing increasing levels of privatization in healthcare³⁹⁰ and other areas.³⁹¹ It is apparent that in Canada caring for one's disabled child is economically risky. This is all the more true where the ideological expectation is that "a mother must be self-reliant and care for children with minimal or no assistance."³⁹² Such expectations, Kline notes, "submerge contradictions between the liberal framework of 'choice' and the coercive and ideological forces in women's lives that make 'options,' such as giving up one's child for adoption, appear viable"³⁹³, as it may do for mothers who can no longer cope on their own with the demands of caring for a child with a severe disability. In fact, 'coping' and 'choice' are key features of caregiving that deeply trouble critical disability theory *and* support law, as will be seen.

As a result of privatization, provinces underfund existing supports such as homecare, even though private care is cost-prohibitive for most mothers. Peter Coyte, who critiques homecare policy in Canada, asserts that with increasing privatization, homecare has formed in "an informational vacuum,"³⁹⁴ a phenomenon that was partially responsible for the care problems described in Ontario's Special Ombudsman Reports. In his report *Between a Rock and a Hard Place*, on the practice in Ontario requiring child custody in order to provide complex care, Ombud Andre Marin expressed that in his opinion:

The Ministry of Children and Youth Services' failure to ensure that parents of children with severe disabilities are not forced to relinquish custody to Children's Aid Societies in order to receive necessary residential placements is unjust, oppressive and wrong.³⁹⁵

³⁸⁷ Coulter *supra* 327 at 31.

³⁸⁸ *Ibid* at 33.

³⁸⁹ Amber Gazso *supra* note 386.

³⁹⁰ Gilmour, *supra* note 281 at 268, refers to a process of reprivatization and commodification.

³⁹¹ Bakker, *supra* note 347 at 545. This includes privatization of state assets and forms of the state she states.

³⁹² Marlee Kline, "Complicating the Ideology of Motherhood: Child Welfare Law and First Nation Women" (1993) 18 Queen's LJ 306 at 328.

³⁹³ *Ibid* at 329.

³⁹⁴ Peter Coyte, *Home Care in Canada: Passing the Buck* (Toronto: Department of Health, Policy Management and Evaluation, University of Toronto, 2000) at iii. Couple this was the missing data on disabled children and one can see a significant problem exists.

³⁹⁵ Ontario Ombudsman, *Between a Rock and a Hard Place*, *supra* note 187 at 42. One of his major findings is that many of the problems are as a result of "acute government maladministration," as the Ombudsman concluded regarding Ontario, but rather administrative glitches in the way the system was set up and perhaps, the training bureaucrats received, *ibid* at 1.

Correspondence between the Ombuds and government¹ revealed that government was aware of the situation.³⁹⁶

There is ample scholarly literature to support the claim that privatizing complex disability care in the manner that it was done negatively impacted women the most. In their analysis of the international literature on parental experience caring for disabled children from 1960-2012,³⁹⁷ Green, Darling and Wilbers found certain features have been constant in parental care of disabled children for over 50 years. The pattern is that it is mothers who provide most of the care,³⁹⁸ something other research claims to be the case approximately 96 percent of the time.³⁹⁹ Some authors refer to this situation as reflecting “a neglected aspect of inequality in caring labour.”⁴⁰⁰ As this form of caregiving has been described as extremely gendered,⁴⁰¹ support law and policy must be formulated with this fact in mind.

Concerning Canada, and using the 2001 Participation and Action Limitation Survey (PALS), Nova Scotian scholars Burton and Phipps examine the economic ramifications of caregiving. Disabled children have been described as expensive,⁴⁰² something that poses hardship on mothers with low incomes. Burton and Phipps also report on explicit and implicit costs associated with caregiving. Implicit costs include missed labour market opportunities, and loss of job benefits. However, any mother experiences this in “staying home”.

In their review of the findings in the literature, Canadian economists Stabile and Allin point out that it is a complicated endeavour to measure the cost of disability to families based on studies undertaken

³⁹⁶ Twelve years ago, on May 12, 2005, the Ontario Ombud provided the then Minister and the Deputy Minister of the Ontario MCYS, a copy of the Ombudsman’s Preliminary Findings in this matter. Marin’s recommendations included restoration of parental custody rights, funding for care, removal of the moratorium on the funding of Special Needs Agreements (SNAs), and administration of SNAs outside the child protection scheme, *ibid* at 44. Correspondence between the Ombuds and government revealed that the government was aware of the situation. In terms of its being aware, The Ontario government committed \$24 million to the problem. This meant that the government perceived complex care needs to pose a problem to families. It allocated \$10 million to assist children with intensive home care needs in 2005 and a further \$10 million in 2006. The Ontario government further stated it would pay \$4 million to children’s treatment centres in 2007. I accessed this information in 2010 and used it in my MA research from a document that I can no longer locate. Sheila Jennings, “Making Them Matter: Disabled Child Rights Litigation in Canada” (assignment for Disability and the Law, 2010, Osgoode Hall Law School and Critical Disability Studies Graduate Program).

³⁹⁷ Sarah E. Green, Rosalyn Benjamin Darling & Loren Wilbers, “Has the Parent Experience Changed over Time? A Meta-Analysis of Qualitative Studies of Parents of Children with Disabilities from 1960-2012” in Barbara Altman & Sharon Barnartt eds, *Disability and Intersecting Statuses: Research in Social Science and Disability* (Bingley, UK: Emerald Group, 2013) 97.

³⁹⁸ Based on their statement that mothers would have preformed care for at-home severely disabled children during the era of institutionalization as well, mothers’ care provision is socially as well as politically assigned.

³⁹⁹ Yantzi & Rosenberg, *supra* note 287 at 302.

⁴⁰⁰ Cohen & Petrescu-Prahova, *supra* note 362.

⁴⁰¹ *Ibid*; Read *supra* note 270.

⁴⁰² See Meyers, Brady & Seto, *supra* note 385.

to date.⁴⁰³ This is the case because different studies use different definitions of disability, and cost features are measured differently, in addition to other reasons they list.⁴⁰⁴ Stabile and Allin note that costs to families fall “in a very wide range.”⁴⁰⁵ Their study would be useful to government as a starting point for examining care costs in its many manifestations.

Borrowing from the language employed in some autism literature, which refers to non-autistic children as *neuro-typical* children, I refer to mothers without disabled children as typical mothers. This is a blunt instrument. Typical mothers forgo the same labour force opportunities as caregiving mothers do, however those mothers with *severely* disabled children are more affected by their circumstances. Lifelong maternally complex care may permanently prevent a mother’s entry and reentry into the labour market.

Ellen Scott has researched some of the hidden costs and consequences of performing care. Scott points out that in the setting of “a neoliberal labor market and privatized systems of family care,” mothers with disabled children struggle chronically with conflicting demands.⁴⁰⁶ Scott’s research also shows that for mothers with disabled children, there is often weak attachment to the labour force, lower or no income of their own over the long term, and accompanying forgone benefits and pensions. This situation positions caregiving mothers as a group at risk of impoverishment, whether they are married or not. Interestingly, no researcher has examined rates of remarriage of mothers with severely disabled children versus mothers with non-disabled children. This is curious since many in family law tout remarriage as a means to mitigate the now obvious risk of future poverty for mothers. Again, assumptions abound where cost and support are concerned. Where the literature examining cost and support fails to fully explore this issue, it is fortunate that many legal cases do.

Burton and Phipps suggest that where there are children with “very severe conditions,” government should support mothers for their performance of a combination of paid work and care, as well as provide income support for lost wages when care requires mothers to withdraw from paid labour.⁴⁰⁷ Their suggestion, while laudable for recommending remuneration, does not address assumptions that

⁴⁰³ Mark Stabile & Sara Allin, “The Economic Costs of Childhood Disability” (2012) 22:1 *The Future of Children* 65 at 69.

⁴⁰⁴ *Ibid* at 67.

⁴⁰⁵ *Ibid* at 70.

⁴⁰⁶ Ellen K. Scott, “‘I Feel as if I Am the One who Is Disabled’ The Emotional Impact of Change Employment Trajectories of Mothers Caring for Children with Disabilities” (2010) 24:5 *Gender and Society* 672.

⁴⁰⁷ Burton & Phipps, *supra* note 204 at 280, 287. Agreeing with their recommendation, I add that tax policy ought also to be reformed as well. A “gender impact analysis” of tax law where mothers of children with severe disabilities are concerned is overdue and something that would lend itself to a feminist critical tax theory lens, such as seen in the published work of Canadian legal scholar, Kathleen Lahey. Although important, this topic is beyond the scope of this dissertation. Kathleen Lahey, “What about Women: Gender Analysis of Discussion Paper on New Brunswick’s Tax System” (Paper delivered at the New Brunswick Advisory Council on the Status of Women, Fredericton, N.B. 31 July 2008) [unpublished] online: Government of New Brunswick, <<http://www2.gnb.ca/content/dam/gnb/Departments/eco-bce/WI-DQF/pdf/en/WhatAboutWomen.pdf>>.

complex medical care⁴⁰⁸ and intensive disability support is women's work. Nor does it address the ethical difficulties this work poses for family members⁴⁰⁹, including to disabled children themselves and their non-disabled siblings.

In considering the complexity of the lived circumstances of caregiving mothers, one is reminded of the notorious case of Irene Murdoch concerning the issue of remuneration/support.⁴¹⁰ My methodology allows consideration of the text of cases as literature, and the *Murdoch* case spawned a feminist legal discourse about the legal right of women to support, and it remains relevant. *Murdoch* is no longer law, and one might assume that the attitudes about women's labour evident in the majority decision have disappeared.

Irene (Ginger) Murdoch co-ran a farm with her husband James (Alex) Murdoch, including when he was away. In addition, she was a caregiver to her husband during his illnesses. The farm work included branding, inoculating and driving cattle. When the Murdochs separated, Irene sought a share of the value of the property. The Supreme Court of Canada found that at the time of their separation, Mrs. Murdoch was not entitled to money from the enterprise, which was in the husband's name, as she had not (they held) made a direct financial contribution to the ranch.⁴¹¹ This finding was based on the opinion that "what [she] had done, while living on the farm [with her husband], was the work done by any ranch wife."⁴¹² Mr. Justice Bora Laskin dissented, stating that denial of an interest in the farm to the wife "would equate her strenuous labours with mere housekeeping chores."⁴¹³ The majority conclusion may be compared to the caregiving labour of mothers of severely disabled children, who are, essentially seen in many areas of law, to provide the same care as any typical mother would do.

Like the word "wife" in *Murdoch*, "mother" in my project is frozen with a socio-legally imbued and historical meaning. The reality is that Mrs. Murdoch made a significant contribution to the family enterprise, as a farmer, even though it was carried out under the legal status of wife.⁴¹⁴ So too, do

⁴⁰⁸ Cf Carnevale, "Daily Living", *supra* note 360.

⁴⁰⁹ For a discussion of ethical implications of homecare concerns, see Peter et al, *supra* note 46; and Manhas & Mitchell, "Going Home", *supra* note 356.

⁴¹⁰ *Murdoch v Murdoch*, [1975] 1 SCR 423, 41 DLR (3d) 367 [*Murdoch* cited to SCR].

⁴¹¹ Mrs. Murdoch argued her family had made a contribution to the purchase of the farm, but this was insufficient to support her claim. The court, having reviewed trust doctrine stated "Difficult as they are to solve, however, these problems as to the amount of the share of a spouse in the beneficial interest in a matrimonial home where the legal estate is vested solely in the other spouse, only arise in cases where the court is satisfied by the words or conduct of the parties that it was their common intention that the beneficial interest was not to belong solely to the spouse in whom the legal estate was vested but was to be shared between them in some proportion or other", *ibid* at 438. The legal doctrines of the law of trusts at the time of this decision protected Mr. Murdoch's property interests, but not his wife's. It is apparent that his interests were considered to be public and legal; to the extent that she had any interests, they were private and non-legal.

⁴¹² *Ibid* at 425.

⁴¹³ *Ibid*.

⁴¹⁴ There was a public response to the injustice seen to have been wrought in *Murdoch*, and a corresponding movement amongst politicized woman who self-claimed "I am Irene Murdoch". See Angela Cameron, Vanessa

caregiving mothers engage in health care provisioning to children with severe medical and physical conditions, even though undertaken under the legal status of mother. That there is no legal doctrine available to remedy this situation (yet), as there was not one (yet) for Irene Murdoch, does not detract from this fact. Certainly, Justice Laskin could see that legal doctrine at that time was unjust. It did not support equality, but rather allowed for a gendered form of unjust enrichment for Mr. Murdoch. A similar point may be made regarding the health care provided by caregiving mothers as required of them by the state.

The caregiving support of severely disabled children has many features. For example, there is emotional labour, the costs of which are omitted in policy and disability rights literature and from mention in support law (although some judges comment on the emotional demands of care in decisions). The “dual role of parenting and medical care provision is tiring and stressful”⁴¹⁵ and the “blurring of parenting” with this kind of caregiving⁴¹⁶ is essentially the conflation of typical childcare with the performance of tasks that fall within the scope of nursing or medicine.⁴¹⁷ Carnevale et al note that “daily life is extremely constrained by extraordinary physical, psychological, social and financial challenges” for mothers of children with complex care needs.⁴¹⁸

Cain has observed that “issues of affect, emotion and care occupy a rather confusing space within the citizenship discourse.”⁴¹⁹ Likewise, medical maternal tasks seem to occupy a rather confusing space in disability rights advocacy.⁴²⁰ Economic costs cannot be separated from these other, less tangible kinds of costs, such as the emotional cost of *having* to perform difficult medical care. Low socio-economic status is understood to be a social determinant of health.⁴²¹ It has been stated that the approach of the current

Gruben & Angela Chaisson, “The Courts Have Turned Women into Slaves for the Men of this World: Irene Murdoch's Quest for Justice” in James Muir, Eric Tucker & Bruce Ziff eds. *Property on Trial: Cases in Context* (Toronto: Irwin Law, 2012). Available online: SSRN

<http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2268731>. Unlike for caregiving mothers in the immediate post *A.(L)*. period, courts in their jurisdiction of equity moved to provide remedies in the area of property division.

⁴¹⁵ Damhnat McCann, Rosalind Bull & Tania Winzenberg, “The Daily Patterns of Time Use for Parents of Children with Complex Care Needs: A Systemic Review” (2012) 16:1 J Child Health Care 26 at 47; see also, Carnevale et al, “Daily Living”, *supra* note 360.

⁴¹⁶ McCann, Bull & Winzenberg, *supra* note 415 at 26.

⁴¹⁷ I was expected to unpack, clean, and dress a very deep post surgical abscess on my then 12 year-old son. Recently a former transplant physician told me this is a challenging task even for seasoned practitioners, and that he was once overcome by this same task, even though wearing a mask and gloves. It made him vomit.

⁴¹⁸ Franco A. Carnevale et al, “What We Know (and Do Not Know) about Raising Children with Complex Continuing Care Needs” (2008) 12:1 Journal of Child Health Care 4 at 4 [Carnevale et al, “What We Know”].

⁴¹⁹ Cain, *supra* note 318 at 67.

⁴²⁰ Medical conditions occupy an uncertain space in critical disability theory. Bodily impairment fits more tidily than does illness into the social model of disability. See Carol Thomas's scholarship in this area, *supra* note ##.

⁴²¹ See Juha Mikkonen & Dennis Raphael. “Social Determinants of Health: The Canadian Facts” (Toronto: York University School of Health Policy and Management, 2010) at 5.

welfare state in Canada prevents the alleviation of negative impacts of low economic status.⁴²² We know that mothers of children with disabilities risk psychosocial problems,⁴²³ and can experience heavy stressors,⁴²⁴ burnout, anxiety, as well as depression.⁴²⁵ It has been found that, “mothers of children with chronic conditions provide a particularly striking example of how health problems experienced by a loved one can ‘spill over.’”⁴²⁶

Thus, the health of caregiving mothers and other family members cannot be understood without considering their ‘family contexts,’ of which low socio-economic status is but one⁴²⁷ and childhood with disability is another. This literature reveals a serious situation. It is crucial that ideologies of ‘good mothering,’ and the newer vision of mothering as healthcare, both of which insist that “capable” mothers meet the many needs of severely disabled children “without assistance from the state”⁴²⁸ must be overcome. There is literature that suggests these ought to be de-linked. De-privatizing care supports in a manner supportive of legal rights needs to be addressed.

The review next examines *public* policy for the presently predominantly private care to severely disabled children. Note that this policy is directed to children, in isolation from their mothers. Caregiving mothers, however, are hidden within government’s narrow eligibility criteria, criteria that fail to consider the caregiving context., including type of housing, The scholarly and grey literature conveys a uniform message, which is the need of reform.

Policy for Severely Disabled Children

Here, I review literature examining the complex arena of childhood disability policy that has arisen in the political contexts of neo-liberalism and the investment state. Theresa Petrenchik states that “though reliable prevalence data for childhood disability in low-income families is currently unavailable, an estimated 30% of Canadian children and youth with disabilities live in poverty.”⁴²⁹ Petrenchik adds that

⁴²² Dennis Raphael, “A Discourse Analysis of the Social Determinants of Health, (2011) 21:2 Critical Public Health 221 at 222. Raphael comments that Canada policy makers lag behind other jurisdictions in the implementation of policy to address such factors.

⁴²³ Julie Barlow et al, “Maternal Stressors, Maternal Wellbeing and Children’s Wellbeing in the Context of Juvenile Idiopathic Arthritis” (2002) 172:1 Early Child Development and Care 89 at 90.

⁴²⁴ Peter Burton, Lynn Lethbridge & Shelley Phipps, “Mothering Children with Disabilities and Chronic Conditions: Long-Term Implications for Self-Reported Health” (2008) 34:3 Canadian Public Policy 359 at 363, 372 [Burton, Lethbridge & Phipps, “Self-Reported Health”]; Nancy Moidrag & Robert Hodapp, “Chronic Stress and Health among Parents of Children with Intellectual and Developmental Disabilities” (2010) 23:5 Current Opinion in Psychiatry 407.

⁴²⁵ Burton, Lethbridge & Phipps, “Self-Reported Health”, *supra* note 424 at 361, 372.

⁴²⁶ *Ibid* at 360.

⁴²⁷ *Ibid* at 361.

⁴²⁸ Amy Salmon, “Aboriginal Mothering, FASD Prevention and Contestation of Neo-Liberal Citizenship” (2011) 21:2 Critical Public Health 165 at 167. This might be qualified in the setting of my project as without robust support from the state.

⁴²⁹ Petrenchik, *supra* note 379 at 7 of 26.

the stress of poverty and exclusion, along with the expense of caring for a disabled child “creates chronic and unnecessary hardship in families.”⁴³⁰ Her use of the term ‘hardship’ is key here. Referencing Hanvey,⁴³¹ she adds that “caring for a child with a disability can be overwhelming ... particularly [for] single mothers” and that government financial support may be the only realistic avenue.⁴³² One can conclude from Petrenchik that many mothers lack the supports to lift them out of poverty despite the fact that there is a literature addressing the problems behind weak or absent support policies.⁴³³ Inadequate supports are not a result of disabled children’s needs not having been made clear in the academic and grey literatures about them, but rather are the result of societal features, such as medical advances.

Advances in medicine are such that severely disabled children are a growing segment of the child population in Canada. There are greater numbers of children surviving trauma, illness, and prematurity,⁴³⁴ as well as congenital conditions. Children with severe medical conditions comprise a unique population, with Peter et al referring to them as forming “a subpopulation.”⁴³⁵ Leiter also notes that “children with disabilities and chronic illnesses are a steadily growing minority of children in the United States.”⁴³⁶ One would expect a careful response from the state to this, especially in light of bold state rhetoric on children’s rights and child anti-poverty strategies.

However, regardless of how disability in childhood is defined, counted, or spoken about publicly, Canadian scholars conclude that supports for disabled children remain inadequate.⁴³⁷ Carnevale et al state that “we know that these children commonly receive sub-optimal care because they ‘fall between the cracks’ due to ambiguous categories, exclusionary criteria or service gaps.”⁴³⁸ In a similar vein, Petrenchik observes that “it is challenging, if not impossible to develop population-based strategies and measure their effectiveness in the absence of meaningful descriptions of the target populations” as well as “in the absence of reliable surveillance and monitoring activities.”⁴³⁹ The CCD has also indicated a need

⁴³⁰ *Ibid* at 3 of 26.

⁴³¹ *Ibid* at 10 of 26, referencing Louise Hanvey, “Children with Disabilities and Their Families in Canada” (National Children’s Alliance, 2002), online: National Children’s Alliance <<http://www.nationalchildrensalliance.com/nca/pubs/2002/hanvey02.pdf>>.

⁴³² Petrenchik, *supra* note 379 at 10 of 26.

⁴³³ Such as Burton & Phipps, *supra* note 204, also in the Canadian context.

⁴³⁴ See Bridgeman, “Children with Severe Disabilities”, *supra* note 182.

⁴³⁵ Peter et al, *supra* note 46 at 1625.

⁴³⁶ Valery Leiter, “The Division of Labour among Systems of Therapeutic Care for Children with Disabilities” (2005) 16:3 *Journal of Disability Policy Studies* 147 at 147.

⁴³⁷ See e.g. Michael J. Prince, “The Governance of Children with Disabilities and their Families: Charting the Public-Sector Regime” (2002) 45:3 *Canadian Public Administration* 389 [Prince, “Governance”]; and M Bach, “Agenda for Action: Policy Directions for Children with Disabilities and Families. Children and Family Series” (North York, ON: L’Institute Roeher Institute, 2000) online: <http://www.eric.ed.gov/ERICWebPortal/search/detailmini.jsp?_nfpb=true&_ERICExtSearch_SearchValue_0=E462818&ERICExtSearch_SearchType_0=no&accno=E462818>.

⁴³⁸ Carnevale et al, “What We Know”, *supra* note 418 at 4

⁴³⁹ Petrenchik, *supra* note 379 at 7 of 26.

for more data in its disability strategy.⁴⁴⁰ The support needs of severely disabled children have not garnered much policy attention, like their mothers' support needs, which are connected. Reasons for this are multifactorial.

Some of the challenges severely disabled children face having their support needs recognized are consistent with Canada's lamentable history respecting marginalized children generally.⁴⁴¹ Politically, there has been little attention given to disability in general. Based on decades of work in the field, disability scholar Michael Prince concludes that disabled children have been largely ignored in public policy,⁴⁴² offering his insight that their interests are poorly linked with the disability policy agenda and children's agendas.⁴⁴³ Prince notes that when Welfare was removed from *Health and Welfare Canada* in 1993 and became part of the Department of Human Resources and Skills Development, federal government responsibility for disability went with it.⁴⁴⁴ At that time, Prince notes, the government's focus turned to 'investing in people' rather than supporting them, and this is partially why disabled children "have been ignored or insufficiently linked with the wider disability and children's agenda."⁴⁴⁵ Prince's observations suggest that space needs to be opened up for disabled children's interests to be made known and acted upon. However, there are other problems facing disabled children *vis-à-vis* support. One of these is the struggle with definitions.⁴⁴⁶

A working definition for the disabled children under discussion in my project was provided in Chapter Two. However, practically speaking, definitions of childhood disability vary. Statistics Canada describes the severity of a disability according to the extent of difficulty a person has in performing certain functions.⁴⁴⁷ This definition has been informed by the World Health Organization's (WHO) International Classification of Functioning, Disability and Health or 'ICF,' which describes 'disability' as a complex interaction between individual impairments, activity limitations, participation restrictions and

⁴⁴⁰ Council of Canadians with Disabilities (CCD), *Annual Report: 2010-2011* (Winnipeg: MB: 2010-2011).

⁴⁴¹ See Strong-Boag, "Children of Adversity", *supra* note 369; and Strong-Boag, *Fostering Nation?*, *supra* note 350.

⁴⁴² Michael J Prince, "Canadian Disability Policy: Still a Hit and Miss Affair" (2004) 29:1 Can J Sociology 59 [Prince, "Hit and Miss"] at 66.

⁴⁴³ This conforms to what Mark Priestly has stated to be the case for disabled children in Britain in "Childhood Disability and Disabled Childhoods: Agendas for Research" (1998) 5:2 Childhood 207.

⁴⁴⁴ HRSDC was previously tasked with dealing with employment and immigration. This is seen to be when the Canadian federal government withdrew from concerns about welfare generally.

⁴⁴⁵ Prince, "Hit and Miss", *supra* note 442 at 73 and 74. More specifically, he states employability of disabled persons became the focus.

⁴⁴⁶ See Dorothy Doolittle, "Welfare Reform: Loss of Supplemental Security Income (SSI) for Children with Disabilities" (1998) 3:1 J Specialists Pediatric Nursing 33; and Jacquelyn Litt, "Women's Care Work in Low-Income Households: The Special Case of Children with Attention Deficit Hyperactivity Disorder" (2004) 18:5 Gender & Society 625. Litt's research reveals how government program eligibility criteria, has continued to be problematic, *ibid* at 637. She argues that already vulnerable mothers are rendered even more so due to frequent shifts in policies and related bureaucratic practices pertaining to children, disability and program offerings. *These are similar to features Canadian policy scholar Michael Prince points to in the Canadian context.*

⁴⁴⁷ Statistics Canada, "PALS: Report", *supra* note 106. PALS was a national survey that collected information about disabled persons.

environmental factors which interact.⁴⁴⁸ Using this definition, Statistics Canada estimates that there were over 74,000 children with severe disabilities in 2006.⁴⁴⁹

Within policy offerings though, definitions of disability vary. A federal government report, which purports to define disability, concludes that recognizing disability actually depends on the goals of a particular government program.⁴⁵⁰ As well, raw data can only tell us so much, however, the issue of whether there is enough research of the right kind must be addressed because ultimately, being able to identify maternal and disability support needs consistently will ensure that those in need of support can be connected to them.

Currently, definitions of disability vary widely and research on what kinds of needs are associated with various disabilities is lacking. For example, regarding children who are technology-dependent, Wang and Barnard note that the “lack of research-based literature in this area has generated difficulty in gaining insights into the issues and experiences of children with long-term technology dependence at home and in their families.”⁴⁵¹ As a result, support policy fails these mothers and children.

While a few studies do proceed by asking what supports should exist,⁴⁵² these appear to emerge from a health services perspective rather than from a social benefits services perspective. The latter is also needed, as services and funding are key supports.⁴⁵³ Experts note that where severely disabled children are concerned, fresh insights are required “to forge new lines of scholarship that will lead to innovative practices and policies, in order to ensure that care-giving responsibilities and costs are distributed fairly and that these children enjoy the rights of citizenship and the entitlements of contemporary childhood”.⁴⁵⁴ In contradistinction to the view that disability requires more research in order to better serve the needs of disabled children, Britain’s Goodley and Runswick-Cole state, “there has been a plethora of research

⁴⁴⁸ World Health Organization, “International Classification of Functioning, Disability and Health (ICF) Framework to Facilitate Interprofessional Education and Collaborative Practice” (Geneva: Author, 2001) online: WHO <http://www.who.int/hrh/news/2014/hrh_icf_framework/en/>.

⁴⁴⁹ Statistics Canada, “The Participation and Activity Limitation Survey (PALS) 2006: Tables” (Ottawa: Author, 2007) online: Statistics Canada <<http://www5.statcan.gc.ca/olc-cel/olc.action?objId=89-628-X&objType=2&lang=en&limit=0>>. Information provided by Cam Crawford.

⁴⁵⁰ Employment and Social Development Canada, “Federal Disability Reference Guide” online: ESDC <http://www.esdc.gc.ca/eng/disability/arc/reference_guide.shtml>, describes disability as a complex phenomenon, and that because of its complexity, there is not a single definition for it that is used across government programs.

⁴⁵¹ Wang & Barnard, *supra* note 383 at 42.

⁴⁵² Diane Hiebert-Murphy, Barry Trute & Alexandra Wright, “Parents’ Definition of Effective Disability Support Services: Implication for Implementing Family-Centered Practice” (2011) 14:2 J Family Social Work 144; S. King et al, “Family-Centred Service for Children with Cerebral Palsy and Their Families: A Review of the Literature” (2004) 11:1 Seminars in Pediatric Neurology 78.

⁴⁵³ See Hiebert-Murphy et al, *supra* note 452 at 151.

⁴⁵⁴ See Carnevale et al, “What We Know”, *supra* note 418 at 5.

studies that have theorized the lives of disabled children.”⁴⁵⁵ They assert that research focuses on barriers that disabled children face. Findings from this review, though, would suggest that while there is a growing literature on the needs of children with less severe disabilities, there remains little research into the lives of children with severe disabilities. Such research will find it necessary to include mothers. Scambler openly states that the needs of those with severe disabilities are inadequately presented in the literature.⁴⁵⁶ If true, it is impossible know what supports their mothers require.⁴⁵⁷ All one can say for certain is that presently, inadequate supports are based on inadequate research.

However, in Ontario, the aforementioned Ombudsman’s Report concluded that provincial research has been undertaken to discern the needs of disabled children in need of care, stating, “It is not the time for further study. This matter has been studied to death, so much so that the appearance is now created that those studies were mere instruments for delay rather than the source of data for decision.”⁴⁵⁸ Notably, also in Ontario, the MCSS has collaborated with researchers to examine respite and residential placements needs, but this was some time ago and was weakly acted upon.⁴⁵⁹ Given what Coulter⁴⁶⁰ and others have stated, which is that there is a disconnection between reports provided to government and government action, more such reports would not be helpful unless they tackled areas that have not been researched, and many past findings still need to be addressed.

In order to grasp why severely disabled children face problems in support policy, attention must also be paid to culture. Green has commented that disabled children fail to “conform to” societal expectations of children *per se*.⁴⁶¹ This may result in their not being fully perceived as being children. If true, this troubling issue has policy ramifications, and may explain the point Sasha Scambler makes above that there is little research about the lives of severely disabled children. More theory is needed on this

⁴⁵⁵ Dan Goodley & Katherine Runswick-Cole, “The Body as Disability and Possibility: Theorizing the ‘Leaking, Lacking and Excessive’ Bodies of Disabled Children” (2013) 15:1 *Scandinavian J Disability Research* 1 at 1. They write about the situation in Great Britain.

⁴⁵⁶ Sasha Scambler, “Exposing the Limitations of Disability Theory: The Case of Juvenile Batten Disease” (2005) 3:2 *Social Theory & Health* 144 at 154.

⁴⁵⁷ The courtroom is one place where mothers are relaying with great specificity what support they need.

⁴⁵⁸ Ontario Ombudsman, *Between and Rock and a Hard Place*, *supra* note 187 at para 143, He reiterates this in the context of mother’s lives, *ibid* at para 163.

⁴⁵⁹ Contact Hamilton for Children’s and Developmental Services, *Hamilton Community Plan for Children and Youth with Complex/Multiple Needs* (Hamilton: Author, May 2005) [Contact Hamilton, *Community Plan*]; Debbie Chiodo et al, “Special-Population Children at the CAS of London and Middlesex: Developmentally Fragile Children and Medically Fragile Children” (London, ON: The University of Western Ontario, 2003). Manitoban research includes First Nations disabled children. For example, studies undertaken through the Prairie Child Welfare Consortium, which is described as a tri-provincial and Northern network involving government. See Don Fuchs, et al, “Children with Disabilities Involved with the Child Welfare System in Manitoba: Current and Future Challenges” in I. Brown et al eds, *Putting a Human Face on Child Welfare: Voices From the Prairies* (Regina: Prairie Child Welfare Consortium, Centre for Excellence for Child Welfare, 2007) 127 online: <http://cwrp.ca/sites/default/files/publications/prairiebook/Chapter6.pdf>.

⁴⁶⁰ Coulter *supra* 327 at 33.

⁴⁶¹ Sarah Green, “‘We’re Tired, Not Sad’: Benefits and Burdens of Mothering a Child with a disability” (2007) 64:1 *Social Science and Medicine* 150 at 151 [Green, “Tired, Not Sad”].

point. It is possible that interlocking oppressions of patriarchy and ableism may combine with a unique form of childism⁴⁶² as an added feature of oppression. This is harder to address than are numbers. The literature about oppression is not of mere theoretical relevance to severely disabled children: it has bearing on the realization of their legal rights to support. Priestly asserts, “[w]ithin the contemporary political discourse of children’s rights there is scope for considering childhood disability as a form of simultaneous oppression in its own right.”⁴⁶³ Priestly believes that the oppression of disabled children has been left unexamined for too long. Goodley and Runswick-Cole suggest that a focus on disabled child policy requires a concentration on the ways in which the ‘disabled child’ is constructed in and by policy, noting that problematically, “developmentalism continues to underpin children’s policy” with its focus on a “normal childhood,” adding that it does so unselfconsciously.⁴⁶⁴ By ‘developmentalism’ they refer to the situation where children are seen to follow a set of predictable steps towards adulthood. Not to do so is construed as being abnormal child development.⁴⁶⁵ This ties in with the comment on childism, above. The important points Goodley and Runswick-Cole make⁴⁶⁶ are that the “impact of the hegemonic status of developmentalism is clear, and policymakers should be cognizant of it. Likewise, Walkerdine suggests that children who cannot meet certain developmental stages when expected to are ‘othered,’ and otherness can only be understood as something ‘at a lower developmental level’.”⁴⁶⁷ According to this logic, disabled children may “fail to match” the developed child of child “policy discourse”.⁴⁶⁸ This mismatch has dire consequences for severely disabled children *and* the mothers who provide their care. One of these is social exclusion of both.

Societal exclusion of disabled people has been a longstanding issue where disability is concerned. Where caregiving mothers are concerned, it leads to social isolation.⁴⁶⁹ This is another hardship faced by disabled children and their mothers, particularly where sole-support, low-income mothers are concerned. In Canada, child welfare systems at one time adopted the ideology of eugenics with the belief in the need to institutionalize disabled children, separating them from society.⁴⁷⁰ Being dynamic, this ideology has changed, and with it societal conceptualizations of disability, but segregation did not entirely vanish with

⁴⁶² Childism refers to the subordination of children in society. See Elisabeth Young-Bruehl, “Childism: The Unacknowledged Prejudice against Kids”, *Time* (26 April 2012) online: Time <<http://ideas.time.com/2012/04/26/childism-the-unacknowledged-prejudice-against-kids/>>.

⁴⁶³ Priestly, *supra* note 443 at 219, writing in the UK.

⁴⁶⁴ Dan Goodley & Katherine Runswick-Cole, “Problematizing Policy: Conceptions of ‘Child’, ‘Disabled’ and ‘Parents’ in Social Policy in England” (2011) 15:1 *International Journals of Inclusive Education* 71 at 80 [Goodley & Runswick-Cole, “Problematizing Policy”].

⁴⁶⁵ *Ibid* at 79

⁴⁶⁶ *Ibid* at 80

⁴⁶⁷ V. Walkerdine, “Beyond Developmentalism?” (1993) 3:1 *Theory and Psychology* 451 at 456.

⁴⁶⁸ Goodley & Runswick-Cole, “Problematizing Policy”, *supra* note 464 at 80.

⁴⁶⁹ Isolation of caregiving mothers is discussed in Donna Thompson’s book, *The Four Walls of my Freedom*.

⁴⁷⁰ Strong-Boag, “Children of Adversity”, *supra* note 369. Sterilization policy was also from this era. Strong-Boag, *ibid* at 423, comments on the placing of “defective” children in “eugenic warehouses.”

the large institutions. Arguably severely disabled children are still largely segregated, in the care of their mothers.

Presently, disabled children and their mothers are the subject/objects of a variety of discourses. Some disability scholars argue that eugenics is still one of these discourses, noted elsewhere as public health promotion aimed at curtailing disability.⁴⁷¹ Health policy research is conducted separately from social policy research, and at times, these areas of research have different or opposing orientations in their discourses. This matters where mothers with disabled children are concerned, because their interests simultaneously encompass both social and health policy domains, irrespective of the discourses. One must consider how childhood disability policy can be coherent under such circumstances. For example, surveillance of so-called congenital anomalies is carried out by the Public Health Agency of Canada.⁴⁷² Their research offers data on childhood disability. However, its purpose is not to ameliorate support, but rather to minimize or eradicate the anomalous births noted in the report that incur increased hospital costs. Birth anomalies are described by the Agency as effectively the result of poor conduct,⁴⁷³ and the Agency's document indicates that such children are flawed, with mothers apparently responsible for this outcome. In this discourse, disability is the result of pathology, one genetic and the other social (maternal conduct⁴⁷⁴). The congenital anomaly registry was created by government after the exposure of pregnant women to thalidomide between 1958-1962. Its purpose is stated to be to detect teratogens.⁴⁷⁵ Thus while advances in pediatric subspecialties continue to extend the lives of children born with or who become severely disabled, the state also demonstrates its interest in identifying 'anomalous' pregnancies.

Concern has been expressed that there appears to be little interest in the well-being of actual disabled children by the federal government.⁴⁷⁶ If one couples the government's goals of eradication of

⁴⁷¹ Aborting disabled children because they are disabled is being described as the new eugenics. The issue of abortion and disability has received media attention. See for example, Roxanne Mykitiuk, "Why care less about the disabled fetus?" *The Globe and Mail* (19 January 2012) online: <<http://www.theglobeandmail.com/opinion/why-care-less-about-the-disabled-fetus/article1358963/>>.

⁴⁷² Public Health Agency of Canada, "Congenital Anomalies Surveillance in Canada. Results of 2006-2007 Survey on Availability of Selected Data Variables in Canadian Provinces and Territories", (Ottawa: Author, 2010) online: PHAC <<http://www.phac-aspc.gc.ca/ccasn-rcsac/sac-cas/sum-res-eng.php>> [PHAC, "Congenital Anomalies"]. Its vision is one of healthy Canadians in a healthier world. It aims to promote and protect health.

⁴⁷³ Maternal obesity, drug use (thalidomide is referenced), folate acid deficiency, older mothers (Down Syndrome) are mentioned as causative of these conditions.

⁴⁷⁴ Even taking a prescribed drug (thalidomide) falls under this heading thus making clear that there is an assignment of responsibility for medical treatment to prospective mothers.

⁴⁷⁵ Health Canada, "Congenital Anomalies in Canada: A Perinatal Health Report, 2002" (Ottawa: Minister of Public Works and Government Services Canada, 2002) online: Health Canada <<http://publications.gc.ca/collections/Collection/H39-641-2002E.pdf>>. There had been provincial surveillance systems as well. For example, the Alberta Congenital Anomalies Surveillance System was founded in 1966 as the Registry for Handicapped Children as described in this same report, *ibid* at xiv.

⁴⁷⁶ As reflected in their absence in the original National Children's Agenda and which various interest groups have drawn to attention. Health Canada, *A National Children's Agenda - Developing a Shared Vision* (Ottawa: Federal-Provincial-Territorial Council of Ministers of Social Policy Renewal, 1999) [Health Canada, *National Agenda*].

congenital anomalies through screening with what reports show, namely that government offerings cannot meet the needs of children and their mothers, one sees a policy design, of sorts.⁴⁷⁷ It is not one based on consensus.

In fact, the entire plethora of discourses on disabled children and their mothers, too many to canvass here, are relevant to challenges mothers face accessing support. These play a role in how caregiving mothers are situated by the state in law and policy. The terrain is crowded, and includes what McKeever termed the feminine caregiving discourse, which arguably can be theoretically subsumed as a group under Rich's theory of motherhood as an institution. Indeed, McKeever refers to mothering children with complex medical care needs as an extreme form of traditional motherhood.⁴⁷⁸

Other discourses include critical disability, socially conservative, political as well as medical/technological discourses.⁴⁷⁹ In all of them, mothers are tightly bound to the care needs of their severely disabled children. For example, technological discourses orient mothers towards healthcare and simultaneously, privatization.⁴⁸⁰ Neoliberal discourses in current health policy implicitly promote home as the ideal place for children to receive health and other forms of care.⁴⁸¹ The health discourse noted above supports the perspective that the severely disabled child is not the ideal child, in either the neo-liberal state,⁴⁸² nor in the social investment state. Such a child may then be deemed as less worthy of state support.

Disabled children themselves have been subjected to discourses, and these likewise impact how disabled children are situated by the state in policy. Goodley and Runswick-Cole explain that "disabled children occupy a complex and contested policy domain in which their status as both 'child' and 'disabled' has to be negotiated and explained (often separately) in the contexts of health, social care, education and leisure."⁴⁸³ Their contested status in areas of policy has further implications for their own

⁴⁷⁷ See Ontario Ombudsman, *Between a Rock and a Hard Place*, *supra* note 187; BCRCY, *Isolated and Invisible*, *supra* note 29; and Contact Hamilton, *Community Plan*, *supra* note 445.

⁴⁷⁸ McKeever, *supra* note 320 at 45.

⁴⁷⁹ *Ibid.* Note these are not water-tight compartments. By discourse I refer primarily a set of ideas and conversations about them.

⁴⁸⁰ This issue was explored by McKeever, *supra* note 320.

⁴⁸¹ See Breen, *supra* note 340.

⁴⁸² Neoliberalism promoted policies concerning children that have been criticized as social Darwinism, particularly troubling in the setting of disability. For example, the 'No Child Left Behind' policy in the United States, which promoted the education system as a socio-economic leveler, was implemented at the same time as it took apart the welfare system was being dismantled. This approach left marginalized children behind. See Rodolfo Leyva, "No Child Left Behind: A Neoliberal Repackaging of Social Darwinism" (2009) 7:1 J Critical Education Policy Studies 365.

⁴⁸³ Dan Goodley & Katherine Runswick-Cole, "Celebrating Cyborgs: Photo-Voice and Disabled Children, Researching the Lives of Disabled Children and Young People, with a Focus on Their Perspectives" (Bristol, UK: ESRC, 2011), at 1 [Goodley & Runswick-Cole, "Celebrating Cyborgs"].

and for their caregiving mother's legal rights.⁴⁸⁴ It is worthwhile examining features of policy that reflects many things, including mothers' status misrecognition, and the harm wrought by non-consensual, full-time, complex care provision, as well as the complex and contested policy Goodley and Runswick-Cole comment on. Together, these intangible features help to explain why legal rights to support for caregiving mothers remain elusive.

Adding to the above complex features of childhood disability, in the Canadian context, such policies have been described as being "in a constant state of flux,"⁴⁸⁵ and as a "hit and miss affair."⁴⁸⁶ Disability policy for children has been variously defined as falling within child welfare, education, social assistance, health, or combinations of these domains.

In fact, disability does fall across multiple sectors and across public and private supports. Moreover, state responses to need reveal a back-and-forth process whereby the state redefines childhood disability, frequently reallocating benefits. This, in turn, demonstrates the contested and fluctuating nature of the disabled child in policy.⁴⁸⁷

This phenomenon demonstrates that in childhood, disability is more than a bodily feature but is politically, and as Green⁴⁸⁸ suggests socially, constructed. The latter may include a maternal construction, which in my view is one of relational value and related obligations. These disparate features make childhood disability elusive to examine and may have contributed to this area of policy being studied by only a few committed academics⁴⁸⁹ and think tanks⁴⁹⁰ with the result that severely disabled children are notable for their absence in much of the literature. This, in turn, results in disabled children receiving less attention than they might otherwise and fewer resources than do other children.

⁴⁸⁴ For example, there is an argument to be made that they are not dealt with as children *per se* in the child protection policy, with the result that they experience rights infringements, along with their mothers.

⁴⁸⁵ *Ibid* at 2. This is challenging those seeking policy change.

⁴⁸⁶ Michael Prince uses this phrase in the titles of one of his articles on Canadian disability policy, Prince, "Hit and Miss", *supra* note 442.

⁴⁸⁷ Something others have likewise shown. See Priestly, *supra* note 443.

⁴⁸⁸ Green, "Tired, Not Sad", *supra* note 461 at 151.

⁴⁸⁹ See e.g. Peter et al, *supra* note 46; Don Fuchs et al, *Report on the Determinants of Children with Disabilities Coming into the Care of Child Welfare Agencies Study: Major Findings, Recommendations, and Future Direction for Policy, Practice and Research* (Ottawa: Centre for Excellence in Child Welfare, 2006); Prince, "Hit and Miss", *supra* note 442; Prince, "Governance", *supra* note 437; Burton, Lethbridge & Phipps, "Self-Reported Health", *supra* note 374; Peter Burton, Lynn Lethbridge & Shelley Phipps, "Children with Disabilities and Chronic Conditions and Longer-Term Parental Health" (2008) 37:3 J Socio-Economics 1168; Burton & Phipps, *supra* note 204; Petrenchik, *supra* note 379; Carnevale et al, "What We Know", *supra* note 418

⁴⁹⁰ Canadian Institute of Child Health, the Caledon Institute, see Sherri Torjman, "R-e-s-p-i-t-e Spells Respect" (Ottawa: The Caledon Institute of Social Policy, 2004) online: <http://www.caledoninst.org/Publications_Search/By_Date/#2004>, The Roeher Institute, and the Canadian Policy Research Networks, see Fraser Valentine, "Enabling Citizenship: Full Inclusion of Children with Disabilities and Their Parents" (Ottawa: Canadian Policy Research Networks, 2001).

As a group, children have been named as a priority on government agendas such as in National Children's Agenda (NCA), a cross-Canada initiative.⁴⁹¹ In 1999-2000, the provinces and territories (except Quebec) participated in formulating a national agenda to find ways to improve policy for children.⁴⁹² A number of different disability rights groups brought attention to the omission of disabled children from these discussions.⁴⁹³ In response to a complaint by one of the groups, as well as input from subcommittees on the status of persons with disabilities and children and youth at risk, an amended vision statement was crafted to address the exclusion of disabled children.⁴⁹⁴ This initiative, ostensibly undertaken on behalf of all Canadian children by the federal, provincial, and territorial ministers, was described as a shared vision.⁴⁹⁵ However, the low visibility of disabled children and their mothers was revealed in their original exclusion from policy discussions on improving the lives of children. This low visibility manifests elsewhere, too. In the academic literature, the unique support needs of mothers of severely disabled children are largely forgotten by experts critiquing existing Canadian policy.⁴⁹⁶

Worthy of note is that the thrust of social investment strategies, ostensibly directed towards at-risk children, is meager where all children are concerned and inimical to the needs of severely disabled children. For example, McKeen states that among the goals of the NCA were the promotion of physical health and "responsible" future citizenship, goals which she argues individualize pathology, rather than seeing societal responsibility. She argues that these programs were not geared towards income redistribution for those in need, and criticizes programs formulated under the NCA as based on moralistic assumptions about poor, racialized or single parents.⁴⁹⁷ McKeen's point harks back to the issue of culture, and within that, class.

NCA drafters appear not to have engaged with the lived realities of mothers with disabled children. McKeen describes the NCA as being a neo-liberal program dressed up to look like support. The NCA ought to have tackled a range of policy issues, such as those identified by disability policy expert Michael Prince. Prince points out that Canadian children with disabilities (i) live with inadequate services

⁴⁹¹ Prince, "Hit and Miss", *supra* note 442; W. McKeen, "The National Children's Agenda: A Neoliberal Wolf in Lamb's Clothing" (2007) 80 *Studies in Political Economy* 151.

⁴⁹² Prince, "Governance", *supra* note 437.

⁴⁹³ *Ibid* at 394.

⁴⁹⁴ *Ibid* at 408 n 6.

⁴⁹⁵ Prince, "Hit and Miss", *supra* note 442 at 80, refers to a Federal, Provincial and Territorial Ministers responsible for social services and the work, Federal-Provincial-Territorial Council of Ministers on Social Policy Renewal, "Public Report on the Public Dialogue on the National Children's Agenda - Developing a Shared Vision" (Hull, Quebec: Author, 2000) at 80.

⁴⁹⁶ See for example the works of Michael Prince, "Governance", *supra* note 437; Prince, "Hit and Miss", *supra* note 442; Michael J. Prince, "Enhancing the Rights and Well-Being of Children, Youth and Families Living with Disabilities" (Speech given to the Annual General Meeting of the Society for Children and Youth of British Columbia, Vancouver BC, 28 May 2004) [unpublished]. The one mention of such mothers occurs in "Hit and Miss", *supra* note 442 at 71.

⁴⁹⁷ McKeen, *supra* note 491 at 168.

and inadequate access to appropriate supports, (ii) have to contend with appropriate services remaining unavailable in many communities, and, where available, inadequate to meet the needs of children with disabilities, (iii) must accept the discretionary funding of services, something he argues implies that disabled children's rights are only privileges, and that (iv) a devolution of policy and services has resulted in inconsistency and a lack of accountability overall in policy.⁴⁹⁸ Prince's analysis makes it evident that policy shortcomings for disabled children exist across the country. Addressing this nationally, however, is challenging as a result of divided constitutional jurisdiction in Canada, as this section of my review has described.⁴⁹⁹

A notable absence of mothers in childhood disability policy reflects the lack of recognition of the centrality of their role in supporting disabled children in all areas, even as the previous omission of consideration of disabled children in policy is pointed out by experts. In *Changing Politics of Canadian Social Policy*, James Rice and Michael Prince state feminists assert that governments develop social programs for women in marginalizing ways.⁵⁰⁰ While commendably, Rice and Prince do reference policy that has targeted unmarried mothers, welfare mothers, divorced women, single women, and sole-support mothers, somehow they fail to address policy pertaining to mothers with severely disabled children, which is curious in light of the findings of Burton, Lethbridge and Phipps addressed in this thesis. This omission lends credence to the view that this mothering population falls below policy radars, even among those policy experts working in the field who are openly supportive of progressive policy agendas for women.

Support-seeking mothers of disabled children, a group that falls within Prince's area of expertise, are in fact marginalized, indeed absent, based on the descriptions of policy agendas. For caregiving mothers to be included in consideration of the right to support for disabled children, the bigger picture of disabled child support policy needs must to be brought to light. Prince himself does point out that

⁴⁹⁸ See Prince, "Hit and Miss", *supra* note 442; and Prince, "Governance", *supra* note 437. Accountability is also addressed in legal literature in the area of administrative law, and some of it addresses childhood disability lawsuits. See Laura Pottie & Lorne Sossin, "Demystifying the Boundaries of Public Law: Policy, Discretion, and Social Welfare" (2005) 38 UBC L Rev 147.

⁴⁹⁹ There are two orders of government in Canada, provincial and Federal, and the Canadian constitution divides jurisdiction of health and child welfare between federal and provincial governments. Child welfare is classically a provincial domain. However, the Federal government is presently before the Federal Court (originally the Canadian Human Rights Tribunal) as the Federal government is being sued over child welfare funding by First Nations in respect of status severely disabled children, who receive some provincial child welfare services on reserve – a topic beyond scope of my project. This dispute is colloqually referred to as the Jordan's Principle case, Jordan was a severely disabled child whose complex care needs were ensnared between different orders of government in a funding dispute. The "principle" refers to a child first policy that provinces agreed to honour, but have had difficulty doing so. First Nations Child and Family Caring Society of Canada, "Canadian Human Rights Tribunal Decisions on First Nations Child Welfare and Jordan's Principle, Case Reference CHRT 1340/7008" (Ottawa: Author, 2016) online: <<https://fncaringsociety.com/sites/default/files/Info%20sheet%20Oct%2031.pdf>>

⁵⁰⁰ James J. Rice & Michael J. Prince, *Changing Politics of Canadian Social Policy*, 2d ed (Toronto: University of Toronto Press, 2013) at 102. The question is, do they agree or disagree?

disabled children were not initially considered in the NCA,⁵⁰¹ but does not take the further step, which is the task of advancing a relational disability policy that includes the rights of caregiving mothers.

There are other problems with advancing childhood disability policy. Where there is an alert as to a policy crisis in a given province, such as has occurred in Alberta in the Martin and Bostick cases, in Ontario, with regard to disability care and child custody loss, in British Columbia with the “unnamed disabled girl” scandal, as well as in the deaths of Angie and Robert Robertson in that province, inquiries or investigations have led to policy recommendations. These are discussed later in the dissertation. Although made public, these recommendations do not appear to benefit other provinces and territories, or even prevent recurrences of tragedy in the same province. The extent to which such recommendations keep disabled children and caregiving mothers safe and well in the province in which they are made and disseminated is an important question. Those working on the ground rather than disability scholars in the ivory tower understand that there was/is a close link between the wider circumstances surrounding harm and deaths and weak or absent support. For example, in the case of the murder/suicide of the Robinsons, Faith Bodnar of Inclusion B.C. described to media a “catastrophic systemic failure” as contributing to their horrific circumstances.⁵⁰² She did not blame the caregiving mother for the bad outcome. Rather, the blame was settled on the Province of British Columbia. Bondar’s statement reveals that disability advocates do not all think alike. Some other disability advocates fail to mention the context of the state failures to support mothers when they report on murder suicide involving disabled children and their mothers.⁵⁰³

The literature suggests that no province is adequately supporting severely disabled children, and given that this is the case, one jurisdiction’s policy may offer insights into ways to improve upon another province’s policy. For this to take place a national initiative, co-ordination and information sharing is needed, instead of the present policy containment. In spite of problems respecting rights where these children and parents are concerned, a legal remedy in the Canadian context is elusive.

Concerning the literature about this situation in Canada, the extent to which supports are available equally across jurisdictions is a salient issue in the examination of supports. It is already known to be a problem with Peter et al indicating that homecare is inequitably available across Canada and inadequately

⁵⁰¹ Prince, “Governance”, *supra* note 437. Prince, “Hit and Miss”, *supra* note 442.

⁵⁰² Faith Bodnar, “Murder-Suicide of Mom and Son with Autism in Prince Rupert; Preventable Tragedy” (24 April 2014), *Inclusion BC*, online: <<http://www.inclusionbc.org/pressroom/newsreleases/murder-suicide-mom-and-son-autism-prince-rupert-preventable-tragedy>>.

⁵⁰³ The “Disability Day of Mourning” website informs the public about filicide of disabled children and youth. It posted a photograph of Robert Robinson, stating that he was murdered through poisoning. Online: <http://disability-memorial.org/>.

funded.⁵⁰⁴ Wait lists for respite and other forms of care and funding for disabled children support comments made by Prince that alone, parents cannot meet the support needs of their disabled children.⁵⁰⁵

Child welfare authorities, having conducted small studies, state that their funding frameworks cannot continue to meet the needs of a population of children not mandated in their funding.⁵⁰⁶ Yet, they have been administering funding for severely disabled children through monies earmarked for children in need of protection. Providing this form of ‘help’ to (primarily) mothers through the provincial child protection legislation has been, and is still perceived by many, as being socially and legally scandalous.⁵⁰⁷ It is troubling that this scandalous policy remains.

This review has traversed a diverse literature that ties into varying aspects of problems of the support needs of mothers with severely disabled children. The need to draw on such a broad literature was the result of the low visibility and uncertain status of mothers with severely disabled children in Canadian society, the politics of privatization, and the cross-disciplinary nature of my project.

⁵⁰⁴ Peter et al 2007 *supra* 46 at 1631.

⁵⁰⁵ Prince, “Hit and Miss”, *supra* note 442 at 64, notes that parents require a range of services.

⁵⁰⁶ See e.g. Chiodo et al, *supra* note 459; and Contact Hamilton, *Community Plan*, *supra* note 459.

⁵⁰⁷ “Ontario Parents Still Asked to Give Up Custody of Special Needs Kids,” *CP24* (18 May 2009) online: CP24 <<http://www.cp24.com/ont-parents-still-asked-to-give-up-custody-of-special-needs-kids-ombudsman-1.380803>>.

CHAPTER FOUR: Once Upon a Time: Representations of Care to Disabled Children

Introduction

This chapter title alludes to fairy tales. Fairy tales occupy the cultural realm, and in my view, they contribute to caregiving mothers status misrecognition. Maternal care to severely disabled children is frequently represented in fanciful ways, contrary to the gritty realities⁵⁰⁸ of much of its performance.⁵⁰⁹ This has arisen as tales get told about caregiving mothers, by the state, by socially conservative disability rights advocates, and by fathers' rights groups. This chapter examines such representations because they contain harmful misinformation, and as such, are inimical to the realization of legal rights for mothers with disabled children, which is my concern.

Arguably no other area of care in Canada is as culturally imbued with such powerful tales, or myths, as is this area. That these fairy tales or myths run directly counter to the realities of maternally complex care demands attention, especially since weak and often unenforceable claims to support and missing legal rights to support are closely tied to cultural stories being told about mothers with severely disabled children.

Caregiving mothers' advocacy must grapple with the power of these tales, which are ideology. As ideology they hide what is really taking place. One way that mothers resist this powerful ideological construction of their care is by demystifying the highly political notions that abound about care burdens in this particular setting. In so doing, they define what maternally complex care burdens actually are. Demystifying 'deideologizes' the fairy tale activities (myths) of the noble and sacrificing special needs mother. One way they do this is through their scholarship and through materials and submissions made in their legal claims for various forms of support and replies to those who seek to end or reduce it.

Maternal disability rights scholars, and mothers' own accounts of disability care, offer a different image of what constitutes caregiving to a severely disabled child, than do fairy tale-like myths. In light of this, I commence my discussion with the concept of 'burdens of care', which will provide a doorway into an analysis of the ways care performed by mothers with disabled children has been represented by the state and by theorists and by the culture.⁵¹⁰ Next, I examine and critique the way mothers have been situated in four conceptual models of disability.

⁵⁰⁸ An example is "coercive" feeding of disabled children with dysphagia, many of whom may refuse food, vomit, regurgitate, splutter, choke, and turn blue during the 5-7 hours a day of feeding they receive from primarily their mothers. Mothers are noted to describe feeding as war, battle, and torture. See Gillian M. Craig and Graham Scambler, "Negotiating Mothering Against the odds: Gastronomy Tube Feeding, Stigma, Governmentality and Disabled Children" (2006) 62 Social Science 7 Medicine 1115 at 1115. Although at 1118 the authors describe participants as "parents", all were women.

⁵⁰⁹ The fairy tale renderings are reflected in the images in Appendix E.

⁵¹⁰ The term 'burden of care' is highly contested and I deal with that contestation in this chapter.

The chapter ends with an examination of *E. (Mrs.) v Eve*,⁵¹¹ the Supreme Court of Canada case that illustrates how individual approaches to legal rights, along with certain representations of care, are implicated in harming mothers with disabled children. In particular, I argue that state representations of care draw heavily on the charity⁵¹², medical,⁵¹³ and also conservative threads from within the social model of disability,⁵¹⁴ and bolster an approach to care illustrated by *Eve*. The representations of maternal care for the severely disabled widely shared in Canadian society suggest that such care is mothering and that mothering of this sort is a *lifelong* obligation. I argue that it is through a process of critical consciousness that mothers escape the shared vision⁵¹⁵ that the extraordinary and under-supported care they provide is a mere variant of typical mothering, and not politically, economically, and physically burdensome, or even particularly important,⁵¹⁶ or interesting.⁵¹⁷

Eve demonstrates that support law has long been bound closely to gender and politics. Law itself has moreover been described historically as injurious to mothers.⁵¹⁸ In present day iterations, as it affects mothers with severely disabled children, support law continues to be political, gendered, and injurious. This is because myths operate to hold in place the view that it is mothers who should provide care, irrespective of their circumstances or the circumstances of their children. Such myths shield the realities of care assigned to women, and as such, they serve to oppress. In this chapter, I expose some of the myths about caregiving mothers of the severely disabled that conceal lived realities of complex care performance. Central to much of this discussion is the concept of ‘burden of care.’

Meanings Conveyed by “Burdens of Care”

The medical meaning of ‘burden of care’ provides that care of the sick or disabled is an economic burden to society, and a social burden to family. As seen in the literature review, the belief that such care is a

⁵¹¹ *E. (Mrs.) v Eve*, [1986] 2 SCR 388, 31 DLR (4th) 1 [*Eve* cited to SCR].

⁵¹² The charity model of disability characterizes support to disabled people as benevolent and philanthropic good works, as opposed to support of disability being a state obligation.

⁵¹³ The medical model of disability situates disability in the individual. It is the individual’s impairments that are problematic.

⁵¹⁴ The social model of disability situates disability in society. It is society and not impairments *per se* that are problematic.

⁵¹⁵ While they may escape the shared vision, it is not a given they will escape onerous heavy care burdens or their ill effects.

⁵¹⁶ Shulamit Almog and Hazan Lotem-Perry, scholars, lawyers, and mothers, wrote “The Ability to Claim and the Opportunity to Imagine: Rights Consciousness and the Education of Ultra-Orthodox Girls”, *supra* note 116. This article examines the education of orthodox girls in Israel and examines the unlikelihood of rights awareness in that cultural setting. They argue that this education and the added sacralization of pregnancy and motherhood pose obstacles to acquiring rights consciousness. This insight is a valuable one with application here.

⁵¹⁷ See Herring, *supra* note 99 at 1.

⁵¹⁸ Kristin Kalsem refers to “The Committee for Amending the Law in Points Wherein it is Injurious to Women” of the 1870s, which critiqued proposed law reform initiatives in Britain that were aimed at infanticide committed by mothers, without considering social context. Such reforms, Kalsem describes, were seen to have “a one-sided narrative about infanticide and attempted to make women’s views legally relevant.” Kalsem, *supra* note 38 at 65.

burden has been rejected by disability rights activists, who have challenged erroneous assumptions about disabled people. However, I claim that this blanket rejection occurred without consideration of all that care comprises, such as who is assigned to perform it, who funds its performance, as well as where and under what conditions it is performed. As such, for those providing maternally complex care, there has been an erasure of the costs of that care.

Saetersdal states that the parents and disabled people she interviewed find that they must live up to norms and expectations if they want to have a voice in what happens to them. She adds that for disabled people and families "... this becomes a further burden if they feel they are unable to live up to what they themselves understand is the "right way" to function as a family."⁵¹⁹ Unfortunately, a result of this is that any discussion of burdens is considered taboo in critical disability scholarship. So too, I add, is reference to or discussion of disability-related grief.⁵²⁰ This is because both burdens of care and grief are seen to have arisen from the medical model of disability, a model seen to pathologize and render tragic both disability and disabled persons.

In mainstream critical disability studies, burdens of care and grief are dealt with as features of the societal rejection of the disabled person;⁵²¹ it somehow implies darkness. However, recent research on mothers with children with a diagnosis of Monosomy IP36 Deletion Syndrome supports contrary findings, namely, that caregiving mothers feel both joy and sorrow.⁵²² However, the critical disability studies approach has thus far failed to confront the multi-faceted features of being the mother of a severely disabled child, including the legal ramifications of care that some scholars have begun to uncover.⁵²³ Historically, mothers in Canada have, under duress, been expected to 'agree' to institutionalize their disabled children and for many, this resulted in grief.⁵²⁴ In dismissing grief as a credible issue, disability rights activists failed to distinguish between public expressions of disability as tragedy versus intimate expressions of loss related to extraordinary maternal care. Risk of loss is an ongoing feature of mothering severely disabled children for some. The horrific potential for disabled child

⁵¹⁹ Barbro Saetersdal, *supra* note 258 at 3.

⁵²⁰ This has itself been burdensome. However other losses may arise too, such as loss of one's hoped for career, or expected liberation from care during one's lifetime. As noted previously, this has not always sat well with caregiving mothers. See e.g. Saetersdal *supra* note 258.

⁵²¹ The topic of maternal grief is beyond the scope of this dissertation. Green, Darling & Wilbers, *supra* note 397 at 123, address it throughout their review of the literature from 1960-2012, finding that mother's grief is often a response to others not appreciating the value of their disabled child to society. This runs counter to a mainstream critical disability approach, which argues that parents of disabled children chronically grieve the lack of a so-called "normal" child. There is support for this position in the medical literature. A touchstone article referred to frequently in critical disability studies is Margaret Freeman Copley & John B. Steiner "Chronic Sorrow in Families of Disabled Children" (1987) 2 J Child Neurology 67.

⁵²² See Fishwick, *supra* note 161.

⁵²³ Elaine Jones, *supra* note 155, interviewed a mother with a child with Down Syndrome who told her family lawyer about her daughter's disabilities, only to have the disability ignored in terms of the support implications of it.

⁵²⁴ See Nic Clarke, "Sacred Daemons: Exploring British Columbian Society's Perceptions of 'Mentally Deficient' Children, 1870-1930" (2004/2005) 144 BC Studies 61 at 11 of 14.

loss, whether it be for legal or medical reasons, remains a heavy burden of care. There is therefore a need to continue to theorize burdens of care and grief in conversations about disability rights.

There is now the view being expressed elsewhere that grief has been simplistically interpreted in the past, with some bereavement experts reporting on the grief expressed by disabled children themselves.⁵²⁵ Indeed, one could refer to a social model of grief, for example, where childhood disability is seen through the lens of the disabling child protection law, and results in child loss.

Having declared my standpoint earlier, my starting point is my claim that heavy burdens of care exist and how I characterize care burdens does not accord with how they have been described in the three mainstream models of disability. In what follows, I will sketch how these different models of disability conceptualize caregiving mothers' burdens. I will argue that a newer characterization of the burdens of care on mothers with severely disabled children will be important to considerations in advancing legal rights to support. Moreover, as alluded to above, and as I explain further below, a maternal process of problematizing the complexities of skilled care, including medical tasks, night work, expensive care and so on, represents first a rejection of how such care is represented in major models of disability, and second, an expression of evolved critical consciousness under circumstances of oppression.

Introduction: Models of Disability in the Context of Disabled Children's Care

As noted in Chapter One, context is crucial to the analysis I undertake. In light of context, I argue that neither the charity nor the social models of disability have accounted for the constraints placed on *mothers* of severely disabled children. Caregiving mothers of severely disabled children face the prospect of a loss of career and income opportunities, a loss of social networks⁵²⁶, and long-term impacts on health that fail to show up in charity and social models of disability.⁵²⁷ These models are alike in the sense that both ignore the particularity of the caregiving mother-disabled child relationship as a pivotal factor in the recognition and assertion of support rights. This omission has implications where the realization of rights may be challenged by their weak development in disability jurisprudence. Frances Olsen describes feminist thought concerning the rights of children as complex and ambiguous, and this is the case respecting the legal rights of disabled children.⁵²⁸

⁵²⁵ Elizabeth J. Bruce, "Grief Trauma and Parenting Children with Disability" (2000) 3:2 *Grief Matters: The Australian J Grief & Bereavement* 27 at abstract and at 31.

⁵²⁶ See Woodgate, Edwards & Ripat, *supra* note 358.

⁵²⁷ See G. Thomas, *supra* note 43. He argued with foresight that there were insufficient supports in place for families with disabled children.

⁵²⁸ Olsen, "Market", *supra* note 134 at 1556. I mentioned her observation in the review as it is an important one.

In reality, disabled children are largely enabled to realize their legal rights with, through, and by actions taken by their mothers.⁵²⁹ In this sense, mothers are their disabled children's primary advocates. As the literature shows, there has been valuable policy research examining the support needs of mothers with disabled children.⁵³⁰ This research reveals that many caregiving mothers require higher levels of support than is presently provided by government. This finding stands in contradistinction to research which either represents care differently, or overlooks important features of it.

Canadian critical disability research that specifically addresses burdens that arise in the setting of care provision to disabled children has been undertaken largely in Alberta. Unfortunately, this strand of research appears to be most interested in children with intellectual disability, cerebral palsy, autism, and Down Syndrome, with a focus on intellectually disabled and autistic children.⁵³¹ While this research claims that it examines a diverse spectrum of childhood conditions, its omissions have significant implications with respect to the generalizability of its findings. Not included in this research are those children who are severely medically, psychiatrically, or neuro-developmentally disabled, but not intellectually disabled, those who have acquired brain injury, those who have survived severe physical trauma or have rare and/or severe genetic or orphan conditions, or any combination of these.⁵³² The research also omits children with complex immune conditions who are medication-emergency room- and technology-dependent.⁵³³ Above all, paradoxically, this research is socially conservative - often lacking a gender perspective, which in my view, is a significant research design flaw considering *who* in families it is doing the primary care provision.⁵³⁴ This research characterizes admitted to burdens as blessings.

While researchers at the University of Alberta examining care issues exclude severely medically disabled children⁵³⁵, medical model research in a medical science paradigm conducted at the University of Calgary has factored gender into its analyses of care burdens borne by mothers with children with medical disabilities.⁵³⁶ Rather than shining a critical disability rights lens on policy, they shine a feminist and

⁵²⁹ As unpalatable as it may be to some strands of the disability rights movement in Canada. Qualitative research conducted by Denise Frankoff, Katherine Runswike-Cole, Patricia McKeever and others has demonstrated this clearly.

⁵³⁰ The Caledon Institute, the Roeher Institute, CanChild, the Bloorview Research Institute, and others.

⁵³¹ See David McConnell et al, "Children with Disabilities and the Fabric of Everyday Life" (Edmonton: University of Alberta, Faculty of Rehab Medicine, Family and Disability Studies Initiative, 2013) online: U of A <<http://www.fdsa.ualberta.ca/~media/Family%20and%20Disability%20Studies%20Initiatives/Documents/FamilyLifeReportrevised.pdf>> at 7 [McConnell et al, "Fabric of Everyday Life"].

⁵³² Orphan diseases are those that are rare, affecting very few children.

⁵³³ Such as my son has. Immune system impairments may be tied to other impairments, difficult to categorize. This has implications for accessing state support to caregiving mothers.

⁵³⁴ Adding female researchers to research teams does of itself not make it feminist or even female friendly research.

⁵³⁵ Within critical disability studies there is tension between those of us with moderately severe or severe chronic illnesses and those otherwise healthy disabled people. In my view, medically disabled (chronically ill or otherwise 'sick') children challenge the social model of childhood with disabilities.

⁵³⁶ See Manhas & Mitchell, "Extremes, Uncertainty, and Responsibility", *supra* note 199; and Kiran Manhas, *The Ethics of Transition: Human, Ethical and Legal Perspectives on Responsibility in the Move to Pediatric Home Care*

ethics lens on support needs, along the lines of McKeever's pioneering work.⁵³⁷ Consequently, their findings are at odds with those I mention from the University of Alberta, as they identify *extreme* burdens of care on mothers. The University of Calgary research points to inordinate responsabilization of caregiving mothers and high expectations of extraordinariness in the care of children whose lives medical research and practice has worked to save.

I argue that socially conservative, and arguably anti-feminist, strands from critical disability advocacy advance interpretations of problems with care as though such interpretations emanate from the social model of disability, when what they arise from is an unwitting combination of the medical and the charity models of disability.⁵³⁸ For example, the views in the socially conservative Alberta research⁵³⁹ that it is not primarily services that are needed, and the view that caregivers do not experience significant stressors misconstrue reality. The view that services are not crucial, or that caregiver stress is a mere "artifact"⁵⁴⁰ is quintessentially a charity model perspective. The charity model of disability relegates support of disabled people to philanthropic endeavors. It raises the key question of support: if not the state, then who? Their answer is 'families', when in fact, it is largely mothers. Rather than opting for the benevolent characterizations of mothers of severely disabled children classically seen in the charity model, more conservative critical disability theorists have engaged instead with a discredited discourse previously emanating from the medical model of disability (psychiatry in particular). That model viewed disability as pathology, and the child's medical pathology was at times linked to the kind of mothering experienced, thus mother-shaming takes place. This approach runs counter to other research from sociology of medicine.⁵⁴¹ These realities point to the need for a coherent and comprehensive theory of care.

It is not only caregiving mothers who are subjected to responsabilizing caregiving discourses and the myths that accompany them. The fact that it happens more widely reveals that it is part of a larger political approach towards care. I argue it is particularly harsh discourse in the setting of disability. For

(Doctoral Dissertation, Department of Medical Sciences, University of Alberta, 2011) [unpublished, archived on ProQuest Dissertations and Theses database]; Manhas, "Sufficiency of Home-Care", *supra* note 182.

⁵³⁷ Patricia McKeever's work appears in the references.

⁵³⁸ It is not only mothers with disabled children who are subjected to caregiving discourses, and the myths that accompany them. Janice Haaken, "From Al-Anon to ACOA: Codependence and the Reconstruction of Caregiving" (1993) 18:2 Signs 321 at 323, provides a critical analysis of the supports groups Al-Anon and ACOA (Adult Children of Alcoholics), both of which grew out of the Alcoholics Anonymous movement.

⁵³⁹ For example that of McConnell et al. *supra* note 531.

⁵⁴⁰ Dick Sobsey refers to there being too much stress on stress. Stress is referred to in relation to the word "artifact" in his and McConnell's work where it is stated that "reported benefits reflect deep, lasting, and transformational changes rather than artifacts of stress, coping, and "sense-making" of an adverse situation (i.e. having a child with disability)." McConnell et al, "Fabric of Everyday Life", *supra* note 531 at 10.

⁵⁴¹ Patricia McKeever and Karen-Lee Miller for example used critical theory to examine the circumstances of mothers with children who were disabled. See their work "Mothering Children Who Have Disabilities: A Bourdieusian Interpretation of Maternal Practices" (2004) 59:6 Social Science & Medicine 1177.

example, Janice Haaken provides a critical analysis of the supports groups Al-Anon and ACOA (Adult Children of Alcoholics), both of which grew out of the Alcoholics Anonymous movement.⁵⁴² Pointing out that Al-Anon and ACOA were founded in the 1980's, she adds that critical theorist Linda Gordon observed that during politically conservative periods, familial abuse becomes couched in psychological language, focusing on individuals as having pathology, while during times of political challenge, structural forms of domination in society are confronted. Her point is that the contemporary co-dependence movement and its literature pathologizes women in relationships with alcoholics, and at the same time fails to address women's oppression as the socially assigned caregivers of alcoholic men, who are, I note, *disabled*. Such a discourse I note creates "caregiving wives", another group of women relationally responsibilized for the care of disabled others.

Haaken states that the co-dependence literature depoliticizes being partnered with or raised by an alcoholic. It is apparent that some of the bases upon which views about co-dependency fall are in the realm of mythology, as such doing ideological work. Part of that work is the responsibilizing of wives and mothers for something that has little or nothing to do with them, but which they are called upon socially to support, and then criticized and constructed as dysfunctional for how they do so. Haaken further claims that pathologizing the female psyche in the manner undertaken in the Al-Anon approach is consistent with conservatism, and that feminists have perceived this approach to be "a retreat from feminist consciousness".⁵⁴³ Such an approach forms part of the larger project concerning the privatization of care under neo-liberalism and I use this example because it shines a light on the process by which an individual woman can become a caregiver through societal expectation alone. The question of rights does not enter into it, care is assumed.

Returning to caregiving mothers, sociological research has concluded that mothers with severely disabled children who perform complex care for them are trapped in an invisible welfare system that involves unpaid, privatized, skilled health care.⁵⁴⁴ This clearly comprises 'burden' at the societal level. This has come about, in part, because where children are concerned, overarching both the medical model of disability and socially conservative strands of the Canadian version of the social model of disability are *a set of shared understandings* about mothers, disability and care. These understandings emanate from the same ideology in whose service these understandings take effect.⁵⁴⁵ What is in the interests of the state in advancing the charity model is also seen in the expressed interests of some mainstream disability rights

⁵⁴² Janice Haaken, "From Al-Anon to ACOA: Codependence and the Reconstruction of Caregiving" (1993) 18:2 Signs 321 at 323

⁵⁴³ *Ibid* at 323

⁵⁴⁴ See McKeever, *supra* note 320.

⁵⁴⁵ Ideology has been described by Louis Althusser as unconscious, as underneath all we do, whether we are aware of it or not. See Phil Smith, "Whiteness, Normal Theory and Disability Studies", online: (2004) 24:2 Disability Studies Quarterly <<http://dsq-sds.org/article/view/491/668>>.

advocates who have historically argued in favour of a gender-neutral “community living” arrangement, without adequate regard to the implications for caregiving mothers. Consequently, extraordinary burdens of care continue to oppress those tasked with shouldering it – caregiving mothers. To better explain, I now examine these models to show how each constructs mothers, disabled children, and responsibility for care.

The Charity Model of Disability – Constructing Motherhood

Ecceshall states that “conservatism”⁵⁴⁶ is characterized by ‘a persistent tendency to glamourize social and political inequalities by endowing them with an aura of righteousness.’⁵⁴⁷ In addition, conservatism sentimentalizes inequality. Above, I commented on the social conservative tendency within disability rights strands to deny that maternal care burdens even exist. The conservative state’s aim is likewise to privatize health and other forms of care that are crucial to disabled children. This aim is facilitated by patriarchy’s charitization⁵⁴⁸ of the notion of care and the passing of the burden of extraordinary care into the hands of mothers.⁵⁴⁹ This is achieved in part by fostering a feminine caregiving ethos comprised of religious devotion, sentimentality, romanticization and personal sacrifice, rather than focusing on the issue of legal rights.⁵⁵⁰ I suggest that mothers internalize these oppressive ideals which form part of a shared consciousness.⁵⁵¹ Mothers support children with complex health care needs and take on complex health care, in what has become an oppressive form of motherhood. It is important not to remain in the realm of abstract theory or fairy tales. If one has been splashed with the puss and blood of one’s wheezing and screaming child on a regular basis, one comes to understand the responsibilities very practically. Along with that, one develops consciousness of having silently acquired carriage of such care.

The charitization of mothers by the state includes symbolic representations that serve to further maintain the status misrecognition of mothers with severely disabled children as a legitimate source of lifelong, free, heavy caregiving labour. British disability rights scholar, Colin Barnes, states that charities

⁵⁴⁶ I include neoliberalism under the heading of conservatism. I assume conservatism to adhere to patriarchal values respecting the role of women and in particular child bearing women.

⁵⁴⁷ Terry Conlin, *Canadian Problems (Volume 1)*, Course Kit. (Faculty of Law, York University, 2013-2014) at 59, referencing Ecceshall.

⁵⁴⁸ I thought I created the word “charitize” but found it being used on the internet in various capacities and it has even been given intellectual property protection in one channel of trade. I use it to mean that caregiving mothers with children with very complex health care needs are deemed to be in the role of a charity by the state, ‘charitably’ giving up careers, pensions, health or liberty in order to provide health care.

⁵⁴⁹ McKeever referred to a “discourse of feminine caregiving”. I draw from her observations in making this statement. McKeever, *supra* note 320 at 37.

⁵⁵⁰ Stacey Clifford Simpican, *supra* note 316 at 219. She writes about the idealization and romanticization of care. She argues that a narrow presentation of dependency, such as Kittays, makes some lives unintelligible in feminist disability studies. I have noted in the literature review that McKeever, *supra* note 320, considered feminine caregiving as a discourse that caregiving mothers were subjected to, in her 1991 doctoral research project.

⁵⁵¹ See Olsen, “Market”, *supra* note 134.

often fail to mention the absence of disabled people's rights in their campaigns, but he refers to one that did in the form of a poster. The poster, from the (then) Spastics Society, bears the images of two infants, with the wording "One has Cerebral Palsy the Other has Full Human Rights."⁵⁵² Below these words is a description of the impairments associated with cerebral palsy, which are stated to be *the reason why the child will be treated differently*, accompanied by the statement: "*In an Ideal World She'd Turn to the Law. In Reality She'll Turn to the Spastics Society.*" The poster lists the areas in which the Spastics Society provided support to the severely disabled child. Barnes's critique rightfully draws attention to ableism, which permits the support needs of children with severe disabilities to fall outside law. However, Barnes neglects to mention that the caregiving work and advocacy of mothers who provide their continual support is also omitted in the poster he describes. Nor does he mention mothers in his critique of the charity model of disability, as it is applied to children with cerebral palsy in Britain. In fact, it is mothers who have most often sought to advance their own and other people's disabled children's rights.⁵⁵³ The marching mothers' campaigns of the 1950s and 1960s provide an example of this.⁵⁵⁴ This activity has been described as being in "the true spirit of volunteerism," which is a gross mischaracterization because it was rights activism and not community service the women were engaged in when marching.⁵⁵⁵ It seems ironic that Barnes, a prominent critical disability theorist who bemoans the charity model, is himself implicated in charitizing the care provided to disabled children. On their own, neither the medical nor the social models have the capacity to "get at" the support rights of caregiving mothers nor as a result, disabled children. Alternatives must be found.

In law, charity is defined as a gift given to the public for general public use.⁵⁵⁶ Legal decisions I present show mothers protesting and contesting their roles as defined by the state through law, which is best characterized as *falling under their willing charity*.⁵⁵⁷ The continued idealization and romanticization

⁵⁵² 'The Spastics Society' of the UK. The electronic publication, Colin Barnes, *Disability Imagery and the Media: An Exploration of the Principles for Media Representations of Disabled People* (Halifax, UK: The British Council of Organisations of Disabled People, Ryburn, 1992), did not have a copy of the poster in it. I emailed Barnes in 2012 but did not receive a response. I also emailed Professor Steven Smith in the UK, who contributed to this book, but he replied that he was not involved with the poster and unable to help. I also contacted SCOPE in the UK, formerly The Spastics Society to inquire about this poster but they did not have a copy. I would have like to have included the image in my appendices. He himself appears to have missed mother's rights in his discussion of the treatment of children with severe disabilities by charities.

⁵⁵³ There is a long history of this. Canadian mothers of children with polio, many of whom died or relied on iron lungs to breath, marched and raised money to draw political attention to the need to fund medical research.

⁵⁵⁴ Money was raised to support medical research for polio. See Appendix F, "Marching Mothers", online: March of Dimes Canada, <<http://www.marchofdimes.ca/EN/AboutUs/about%20modc/history/Pages/marchingmothers.aspx>>.

⁵⁵⁵ Moreover, marching is more akin to protest than it is to volunteering in the community. The fact that it was mothers who marched, moreover those with disabled children somehow seems to hide that fact.

⁵⁵⁶ *Black's Law Dictionary* 5th ed, *sub verbo* "charity".

⁵⁵⁷ I am reminded here of the title of a UK journal article by Janet Read, "There Was Never Really Any Choice", *supra* note 315 at 561. Read quotes a mother as stating "We are ordinary people coping with extra pressures, extra illness, extra work."

of the care mothers provide is characterized in the culture as both a gift bestowed upon her and a gift given by her.⁵⁵⁸ An exemplification of this may be seen in the numerous references to a poem written by American newspaper columnist, Erma Bombeck.⁵⁵⁹ In referring to a mother of a disabled child the author writes: “Her patron saint will be the person looking back at her when she gazes into a mirror.”⁵⁶⁰ In this representation the mother is heroic.⁵⁶¹ Such representations of caregiving mothers construct the burdens of caregiving as blessings and mothers with ‘special children’ as self-sacrificing. Many online groups display sections of the Bombeck poem, some referring to the mother of a disabled child as *Une Mère Spéciale* and *La Maman Spéciale*.⁵⁶² Bombeck’s poem, which describes the virtuous characteristics of mothers of disabled children, relays these traits as being the result of chosen women rising to the noble challenge set for them by God. Surmising what God would say when allotting a disabled child to an unsuspecting mother, Bombeck wrote, “I will permit her to see clearly the things I see - ignorance, cruelty, prejudice - and allow her to rise above them...I will be at her side every minute of every day of her life, because she is doing my work as surely as she is here by My side.”⁵⁶³ According to this narrative, God’s work is what mothers of children with disabilities are performing, whether they want to or not.⁵⁶⁴ The Canadian institution of motherhood has also been shaped by Christian values and cultural expectations that women devote themselves to motherhood,⁵⁶⁵ no matter the long-term personal costs.⁵⁶⁶

⁵⁵⁸ See Kline, *supra* note 392.

⁵⁵⁹ She also wrote children with cancer in this same time frame. Erma Bombeck, *I Want to Grow Hair, I Want to Grow Up, I Want to go to Boise: Children Surviving Cancer* (Toronto: HarperCollins, 1989). It was based on her involvement with children with cancer.

⁵⁶⁰ Erma Bombeck, “The Special Mother” in Erma Bombeck, *Forever, Erma: Best Loved Writings from America’s Favorite Humorist* (Riverside, NJ: Andrews McNeel, 1980) [Bombeck, “The Special Mother”].

⁵⁶¹ See Fisher & Goodley, *supra* note 192. Her other experience is to be pitied according to these same authors.

⁵⁶² Some books also point to the “specialness” and the notion of a calling, see e.g. Leticia Velasquez, *A Special Mother is Born: Parents Share How God Called Them to the Extraordinary Vocation of Parenting a Special Needs Child* (Bloomington, In: Westbow Press, 2011).

⁵⁶³ Bombeck, “The Special Mother”, *supra* note 560.

⁵⁶⁴ I later introduce the notion of coercive care in this context. Bombeck’s narrative continues, *ibid*: “‘Finally he passes a name to an angel and smiles.’ ‘Give her a blind child.’ The angel is curious. ‘Why this one, God? She’s so happy.’ ‘Exactly.’ says God. ‘Could I give a child with a handicap to a mother who does not know laughter? That would be cruel.’ ‘But has she patience?’ asks the angel ‘I don’t want her to have too much patience, or she will drown in a sea of self-pity and despair. Once the shock and resentment wear off, she’ll handle it.’”

⁵⁶⁵ Activities of a variety of Churches, including the United Church, which is a Canadian Church created by an Act of Parliament in 1925, have run Canadian Girl’s In Training (CGIT) programs. CGIT was founded in 1915 with start up support from the YWCA, Anglican, Baptist, Presbyterian and Methodist Churches. See Margaret Prang, “‘The Girl God Would Have Me Be’: The Canadian Girls in Training, 1915-1939” (1985) 66:2 *Canadian Historical Rev* 154. CGIT became a formal program of the Canadian Council of Churches. Its mandate for girls is: “As a Canadian Girl in Training, under the leadership of Jesus, it is my purpose to Cherish Health, Seek Truth, Know God, *Serve Others and thus, with His help, become the girl God would have me be*”. (My emphasis.) The assumption in CGIT was that “...the vast majority of girls would become wives and mothers. They must be equipped with the knowledge and attitudes that would enable them to establish and sustain Christian marriages and to bring up their children in a changing world...” *Ibid* at 169. According to Prang materials on vocations in CGIT programs were provided, but “The Queen of them All” was motherhood. *Ibid* at 170.

Passive acceptance is apparent in Bombeck's narrative, as is the idea that mothers have the help they need (from God's benevolent gaze rather than from the support of the state). This 'feminine' passivity is far from the counternarrative provided by caregiving mothers in academic research and in their litigation for support, where they state they require both support and recognition.⁵⁶⁷

The vaunted ideal of the special mother is used by Bombeck to explain the extraordinary demands placed on and met largely by mothers as a holy assignment, and she is not alone in this approach.⁵⁶⁸ In a discussion about Franco Carnavale's research in the Montreal Children's Hospital Study, in which she was a participant, Carol Levine contests being "lauded as saintly," stating that she equates this with sacrifice and suffering.⁵⁶⁹ Jonathan Herring affirms that, "mothers are glorified", noting that "there are serious dangers with the glorification of motherhood."⁵⁷⁰ One of these, he states, is that anyone who does not meet the standard is seen to be a failure. He also notes that caregiving by mothers is assumed. His insights are particularly on point in a consideration of those mothers who perform extremely challenging forms of complex care, and who are judged harshly for all outcomes of its performance.⁵⁷¹

Mothers and the Medical Model of Disability

In the medical model, the person with the disability is viewed through a scientific lens and identified as having pathology.⁵⁷² Illness and disability are both seen as features that medicine ought to fix. There was at one time a conflation of the medical meaning of the burden of disease with the notion that an ill person *is herself a burden*, and those with disabilities were seen to impose burdens on their families and upon the state. 'Burden' also became a term that was used in public policy. The provision of care to persons with

⁵⁶⁶ See McKeever, *supra* note 320, this PhD thesis carefully described the ways in which a group of mothers of chronically ill and technology dependent children both complied with and resisted the social expectations placed on them through both feminine caregiving (and medical technology) discourses. Her pioneering research is important because it showed the heavy effects this sort of feminine caregiving had on mothers' wellbeing in the social and policy milieu in place at that time.

⁵⁶⁷ See Green, *supra* note 461. See also Gail Landsman, "Reconstructing Motherhood in the Age of 'Perfect' Babies: Mothers of Infants and Toddlers with Disabilities" (1998) 14:1 Signs 69.

⁵⁶⁸ See Olsen, "Market", *supra* note 134 at 1518. It is interesting that American suffragette Elizabeth Cady Stanton, is reported to have "urged the legislature to stop treating marriage as "a kind of half-human, half-divine institution", adding "if marriage is to be viewed as a civil contract...let it be subject to the same laws which control all other contracts." In this same essay, Olsen quotes Harriett Taylor Mill in a paper on the enfranchisement of women dating from 1851 as insisting that "progress in family relations lags behind economic progress: and tied this lag to a failure in justice. *Ibid* at 1519. The points these first wave feminists raised must still be argued, for the project of removing women's work from the realm of the divine and making it separate from other economic aspects of life remain with us today, and especially where mothers care full time for children with severe disabilities.

⁵⁶⁹ Carol Levine, "Acceptance, Avoidance and Ambiguity: Conflicting Social Values about Childhood Disability" (2005) 15:4 Kennedy Institute of Ethics J 371 at 372.

⁵⁷⁰ Herring, *supra* note 99 at 7.

⁵⁷¹ For example, having to resort to child protection regimes after many years of unremunerated medically oriented care.

⁵⁷² Hence this model is also referred to as the individual model of disability.

medical conditions by family has also been referred to as a burden in the medical literature. This approach essentialized disabled persons as being their disability. At the same time, in medicine, as in wider society “there is a social belief that children’s needs should be met by parents, not recognizing the special burden of complex medical care.”⁵⁷³ However, more recently, medicine has become increasingly aware of disability rights and some health professionals engage with disability rights discourses, including in pediatric medicine. Furthermore, more health care professionals appear to be taking a more holistic approach to burdens of care. Thus, I argue there are signs of a more nuanced meaning of burden of care arriving in medicine.⁵⁷⁴ What is still missing, however, is a medical model analysis of the need for support once disabled children leave the hospital. In neglecting to perform and act upon this analysis, medicine implicitly depends on the care needs of the severely disabled and their caregiving mothers being met through models of care promoted by a charity model, a model that is consistent with conservative and patriarchal strands within disability rights.

Some medical research has examined what may be burdens to disabled children and their mothers in the context of health care, including with respect to the burden imposed in medicine by ideas about the normative body.⁵⁷⁵ The research team involved in the study *Stress and the burden of care in families with children commencing renal transplant therapy* found their burden of care assessment to be useful in identifying family members’ need of support in caring for their sick child.⁵⁷⁶ The researchers examined a range of issues to find out what resources parents of medically disabled children lacked. In this care setting, burdens related to the demands of the child’s treatment included poor housing, low income, transportation, as well as the demands of medication administration, the requirements of the dialysis and supplementary feeding of the child. The environment was perceived as creating potential burdens of care, in other words, and so, burden was positioned socially.

This study included mothers in the United States and Great Britain demonstrating high levels of stress, anxiety, and depression. Their levels were higher than those of fathers, with many mothers exhibiting anxiety disorder. Mothers also reported higher ‘intrusion of illness’ scores than did fathers,

⁵⁷³ Peter et al, *supra* note 46 at 1635.

⁵⁷⁴ I would add also that medicine and public health were at the forefront of pointing the role of poverty in childhood medical disability. For example, physicians publicly point out the role that mould in low-income housing plays in severe chronic respiratory illnesses such as asthma, of poor people’s children. See Robin L. Nobleman, “Addressing Access to Justice as a Social Determinant of Health” (2014) 21 Health LJ 49 at 65.

⁵⁷⁵ See Barbara Gibson & Gail Teachman, “Critical Approaches in Physical Therapy Research: Investigating the Symbolic Value of Walking” (2012) 28:6 Physiotherapy Theory & Practice 474; and Peter Rosenbaum & J.W. Gorter, “The Five “F” Words in Childhood Disability: I Swear This Is How We Should Think!” (2012) 38:4 Child Care Health and Development 457.

⁵⁷⁶ Alan R. Watson, “Stress and the Burden of Care in Families with Children Commencing Renal Transplant Therapy” (1997) 13 Advances in Peritoneal Dialysis 300, online: <<http://www.advancesinpd.com/adv97/pt5stress64-97.html>>.

which the researchers found made sense, with their being the primary caregivers in most cases. Those with a higher burden of care had higher levels of stress, anxiety, and depression.⁵⁷⁷

The drawback typically cited respecting the medical approach is that in seeking to alleviate burdens of care, the focus tends to be on the child's "pathology" rather than on the lack of family supports. However, I suggest that this study, in which criteria for burdens of care were expanded beyond those of the child's medical condition, as is typical in the medical literature, demonstrates that some medical research now uses wider criteria. In this research, the BCA assessment arose out of multidisciplinary team conversations about families whose children were being admitted to the facility. Thus I argue medical approaches may be shifting in part due to the influence of disability rights and sociological discourses having drawn medicine's attention to the impact of environment on health, as well as to social determinants of health.⁵⁷⁸

Mothers and the Social Model of Disability: Contested Space

In this section, I address the social model of disability and the tensions between this model and the lived realities of maternal care and support of severely disabled children. I hone in on a particular thread within disability rights scholarship that is advanced through the social model, and expose gender biases apparent within that approach. For example, to the extent that disability rights advocates have been critical of child welfare services for disabled children, without also factoring in caregiving mothers' need of support, the social model becomes problematic for mothers and for their disabled children.⁵⁷⁹ In the social model, disability is seen through the lens of a disabling social environment with little reference to medical impairments. This model claims burden of care as a concept refutes the autonomy of disabled people.⁵⁸⁰ Critiques from the social model have shown this to be true for disabled children, whose presence has, in

⁵⁷⁷ Evidence of the link between harm to health in the setting of care for disabled children has been referred to in court decisions where mothers have sought greater levels of government funding for respite. The medical evidence provided in *Nova Scotia (Community Services) v E.M.*, 2011 NSSC 12 [*E.M.*] for example underscores that in courts of law, as in paediatric medicine, burden of care to mothers is a credible concern and the question of mothers love for their children is not something countenanced as a relevant factor as it is a given.

⁵⁷⁸ In a different medical article about children with cerebral palsy, the authors comment that we are witnessing a "sea change" in how we (as in medicine) see disability and in particular in childhood disability. See Rosenbaum, Peter & J.W. Gorter. "The Five "F" Words in Childhood Disability: I Swear This Is How We Should Think!" (2012) 38:4 Child Care Health & Development 457 at 457.

⁵⁷⁹ See for example Michael Oliver & Bob Sapey, *Social Work with Disabled People*, 3d ed (London: Palgrave Macmillan, 2012). Only a few pages of this book are devoted to the needs of disabled children.

⁵⁸⁰ Use of the word 'care' is critiqued by those in the social model of disability, as a word that denies persons with disabilities their autonomy. It has been thus described as patronizing and as implying dependency. See Ian Bynoe, Mike Oliver & Colin Barnes, "Equal Rights for Disabled People: The Case for a New Law" (London: Institute for Public Policy Research, 1991) online: <<http://disability-studies.leeds.ac.uk/files/library/bynoe-equal-rights-for-disabled-people.pdf>>.

addition, been traditionally interpreted as a family tragedy.⁵⁸¹ Few theorists researching within the social model of disability examine care of severely disabled children in Canada. A well-known theorist who does has argued “There is Too Much Stress on Stress.”⁵⁸² In other words, the assertion is that too much emphasis is placed on care burden in mainstream consideration of the lives of disabled children. This point I contest. For if it is to be believed, it holds negative implications for caregiving mothers and their disabled children. Moreover, I do not share the views of these scholars as to what does and does not comprise caregiver burden, nor do I agree that mothers are simply ‘caregivers’. The public domain in which “care” for children and mothers is provided is that of provincial child welfare jurisdiction, and it is to that domain that I now turn.

Support Domain of Child Welfare

Whether one employs the social or the medical model, one cannot discuss burden and care without also discussing the law and policy domain of child welfare. The field of child welfare also relies on scholarship, including human rights scholarship, to theorize how disabled children are situated. Such scholarship, to which child welfare scholars defer, stated some time ago that, “the pervasive nature of the medical model within disability services” isolates disabled children, and that “at many levels the awareness of children’s rights does not penetrate the world of disabled children.”⁵⁸³

Where coming to the attention of child welfare authorities is concerned, disabled children do share some similarities with non-disabled children. The non-disabled children with whom they share similarities are those described by Strong Boag, as children living with ‘adversity’.⁵⁸⁴ Their mothers as a group are usually grossly under-resourced. The problem is that a child’s severe *medical* condition ought not to be constituted as an adverse child *welfare* concern. It is a *long-term health care* issue. Related to this, mothers’ inability to provide long term medical care ought not to be construed as *her* being under resourced.

The differences that disabled children have as compared to non-disabled children in terms of coming to the attention of authorities are manifold. One is that their caregiving mothers actively seek out care from child welfare. Another is that disabled children are taken into care more often than are non-

⁵⁸¹ See Penelope M. Kearney, “Between Joy and Sorrow: Being a Parent of a Child with a Developmental Disability” (2001) 34:5 *Journal of Advanced Nursing* 582 at 582.

⁵⁸² Dick Sobsey, “Too Much Stress on Stress? Abuse and the Family Stress Factor” (1990) 3:1 *Newsletter of the American Association on Mental Retardation* 2 at 8.

⁵⁸³ Lesley Campbell, “Rights and Disabled Children” in Bob Franklin ed. *The New Handbook of Children’s Rights. Comparative Policy and Practice*. (New York: Routledge 2002) 197 at 197.

⁵⁸⁴ Strong-Boag notes that children with many differences were together labeled ‘special’ by child welfare authorities in the post war era. Strong-Boag *supra* 369 at 418.

disabled children.⁵⁸⁵ Related to that, as I discuss later, disabled childrens' entitlement to remain in the custody of their mothers is more tenuous than for many other children (an exception to this is when their mothers are marginalized by extreme poverty, Indigeneity, or have psychiatric⁵⁸⁶ or other disabilities).⁵⁸⁷

Child welfare services are intended to be for the dual and related purposes of support of (primarily) mothers and for the protection of children. However, mothers who seek health care from child welfare jurisdictions are placed under the child protection gaze. The very act of a caregiving mother seeking care and support leads to the application of little discussed lens of health care neglect, which is misplaced in this context (as I discuss elsewhere). This practice fits with what Melinda Giles describes as "the social production of risk". She states that risk has been more heavily embedded in child welfare since 1997,⁵⁸⁸ and she points out that risk-management has become the primary focus in child welfare.⁵⁸⁹ This may help us to understand *in part* why the focus in disability rights has centered on risk of abuse. Meanwhile the scholarly focus in child welfare⁵⁹⁰ has been on trying to understand the societal and familial factors that result in "the over-representation of children with disabilities" in the child welfare system".⁵⁹¹

It has been documented that in Canada disabled children are taken into state care more often than are non-disabled children.⁵⁹² A prominent researcher in the United States found that disabled children were more often found to be neglected and abused (maltreated) by child welfare authorities.⁵⁹³ Some social model theorists claim that child welfare professionals have, in an ableist manner, "constructed the disabled child *as* stress"⁵⁹⁴ and this is the reason why they are more often involved in child welfare. This

⁵⁸⁵ In Canada this has been well documented in child welfare research in Manitoba for example. For example in the work of Don Fuchs referenced at note 591.

⁵⁸⁶ Judith Mosoff describes the intersection of mental health law and child protection law, claiming that the state asserts its power over women in a like manner in both areas of the law. Judith Mosoff. "Motherhood, Madness and Law" (1995). University of Toronto Law Journal 45,107 at 108.

⁵⁸⁷ That disabled mothers are vulnerable to child loss to the state and to custody battles has been documented in the literature. See for example, Daphne E. Glaun and Patricia F. Brown. "Motherhood, Intellectual Disability and Child Protection: Characteristics of a Court Sample"(1999). Journal of Intellectual and Developmental Disability, 24:1. Susan Kerr, "The Application of the Americans with Disabilities Act to the Termination of Parental Rights of Individuals with Mental Disorders" (2000). Health, Law and Policy, 16, 387.

⁵⁸⁸ Melinda Vandenberg Giles. "From "Need" to "Risk". The Neo-Liberal Construction of the Bad Mothers" (2012). Journal of the Motherhood Initiative 3:1, 112 at 114.

⁵⁸⁹ *Ibid* see discussion throughout her paper and at 129.

⁵⁹⁰ In Critical Disability Studies Canada's examples are Dick Sobsey, and Britains Michael Oliver and Jenny Morris. In child welfare, Sheila Marchenski, Andrea Mudry and Linda Burnside have conducted research in this area.

⁵⁹¹ Don Fuchs, Linda Burnside, Shelagh Marchenski and Andrea Mudry. Children with Disabilities Receiving Services from Child Welfare Agencies in Manitoba (2005). Centre for Excellence of Child Welfare. Fuchs states that disabled children are at greater risk for both maltreatment and neglect.

⁵⁹² Fuchs et al. *Ibid* note 591. These scholars state that disabled children are at greater risk for maltreatment.

⁵⁹³ Patricia M. Sullivan and J.F. Knutson. "Maltreatment and Disabilities: A Population Based Epidemiological Study".(2000) 24:10 Child Abuse and Neglect 1257.

⁵⁹⁴ Dick Sobsey, *Children with Disabilities in Child Welfare*, PowerPoint Presentation, (University of Alberta, 2013) online: <<http://casw.umn.edu/wp-content/uploads/2013/05/Sobsey.pdf>> [Sobsey, "Children with Disabilities"].

construction, it is argued by such theorists, places the blame for abuse on the disabled child, as according to this theory, it impacts child welfare authority evaluations of maternal capacity to parent the disabled child who has come to their attention. However, this is an inaccurate characterization of what takes place in child welfare interventions.⁵⁹⁵ In fact, the medical model, which I argue includes child welfare, also accounts for disabled child abuse and neglect by examining factors widely understood to lower parental capacity to provide care.⁵⁹⁶ This is not at all the same thing as blaming the child. This is not to say that child welfare workers are never ableist. I argue where severely disabled children are concerned it is not as black and white as these two differing approaches would suggest.

Disability is one among the many features of family life that may be evaluated in a child protection investigation. Parent capacity is another.⁵⁹⁷ Child welfare professionals take the position that parents (mothers most often) must have a ‘good-enough’ ability to meet the additional needs of a disabled child.⁵⁹⁸ What proponents of the social model consider is taking place in child welfare investigations into ‘not good enough’ care, is that disabled children considered by social workers to be ‘abuse-prone’⁵⁹⁹ are essentially held accountable for their own abuse.⁶⁰⁰ This purported ‘cause and effect’ approach to disabled child abuse is referred to in the social model of disability as the “dependency-stress model” of abuse,⁶⁰¹

⁵⁹⁵ When social workers in Canada evaluate levels of family functioning, they do consider the presence of a disabled child as adding to demands placed on the caregiver. This is not the same thing as “constructing” the disabled child as stress. Impairments are seen to present as risk factors in the context of a parent capacity evaluation however. This ought to be interpreted as impairment being one factor among many that the caregiving mother must be able to accommodate. This is not the same thing as a work place accommodation, since it is vastly more complex than that. See Public Health Agency of Canada, “Canadian Incidence Study of Reported Child Abuse and Neglect, 2008: Major Findings (Ottawa: author, 2010) online: PHAC <<http://www.phac-aspc.gc.ca/cm-vee/csca-ecve/2008/index-eng.php>> [PHAC, “Canadian Incidence Study”].

⁵⁹⁶ Decisions in child welfare are made by social workers who elicit the professional opinions of those in medicine and its allied professions, including about medical evidence and opinion on whether to bring the matter to court. This is shown in the speakers invited to a conference entitled “‘Beyond Best Interests’ Parenting Capacity in the Child Welfare Context”, part of the 311 Open Bar Series held by the Family Lawyers Association, Ontario, 5 February 2003. This workshop discussed evidence the court needs to assess parent capacity. Speakers included a psychiatrist, a psychologist, a social worker, a lawyer, and was chaired by a Judge.

⁵⁹⁷ A number of things lower parental capacity. Bereavement would be one example. In a family with two severely disabled children therefore, the death of one child may lower the capacity of a sole mother to care for the other. This may result in neglect, or it may not. A terminally ill parent may struggle with capacity to parent. Parent capacity is impacted by much more than the word “stress” implies.

⁵⁹⁸ See Julia Krane & Linda Davies, “Mothering and Child Protection Practice: Rethinking Risk Assessment” (2000) 15:1 *Child & Family Social Work* 35 at 42. The authors state “social workers in child protection must make judgments as to what constitutes ‘good enough mothering’ in any particular case, but the statutory context of their practice necessitates an emphasis on children’s needs and interests.”

⁵⁹⁹ Social model proponents attribute the articulation of this approach to two American graduate students from articles they published in the 1970’s and whose work I address below.

⁶⁰⁰ “Good enough” parent is a term of art in child welfare emanating from the work of Donald Winnicott, specifically, “Transitional Objects and Transitional Phenomena – A Study of the First Not-Me Possession” (1953) 34 *Intl J Psycho-Analysis* 89.

⁶⁰¹ Dick Sobsey, “Exceptionality, Education and Maltreatment” (2002) 10:1 *Exceptionality* 29 at 47 [Sobsey, “Exceptionality”]. Sobsey also references this model of abuse in an early book of his: Dick Sobsey, *Violence and Abuse in the Lives of People with Disabilities: The End of Silence and Acceptance?* (Baltimore: Paul H Brookes,

seen to be an ableist fallacy. According to this model, “[c]hildren with disabilities often are considered to be sources of family stress” and this belief is purportedly the foundation for the dependency-stress model of abuse.⁶⁰² Manders and Stoneman, referring to a proponent of this model, Alberta advocate Dick Sobsey, state that after reviewing the literature, “Sobsey concluded that caregiver stress may have a role in triggering discrete outbursts of abuse but is not a significant cause of maltreatment...many CPS workers still focus on parent stress and burden.”⁶⁰³ If Sobsey concluded that parental stress triggers abuse, however discretely,⁶⁰⁴ then that feature needs attention paid to it on that basis. However, the conclusion above implies that any focus by child welfare professionals on burdens of care is misplaced, since stress has been found *not* to be a significant cause of disabled child maltreatment.⁶⁰⁵ Never mind that expert evidence on child maltreatment from child welfare would disagree with Sobsey’s conclusion.⁶⁰⁶ The way that stress is defined, what the context is, and who is under discussion, are all relevant to care.

Maternal distress and care stressors are not a tangential issue of rights to support of caregiving mothers with disabled children., they are central to it. If those in the field of child welfare can be convinced that caregiving mothers exaggerate or misconstrue the nature of the stressors they report⁶⁰⁷, then it is the mothers who are to be pathologized, in one manner or another. It may then be transformed

1994). Caution must be exercised in not transplanting critical disability theory about structural violence towards disabled persons in society to the mother-child relationship.

⁶⁰² Jeanette Manders & Zolinda Stoneman, “Children with Disabilities in the Child Protective Services System: An Analog Study of Investigation and Case Management” (2009) 33:4 Child Abuse & Neglect 229 at 229.

⁶⁰³ *Ibid* at 230. CPS refers to child protection services in the United States.

⁶⁰⁴ *Ibid*. The authors state “Children with emotional/behavioural disabilities are viewed as especially potent sources of parental stress because of their difficult behaviours (Sobsey, 1994). After reviewing the relevant literature, Sobsey (2002) concluded that caregiver stress may have a role in triggering discrete outbursts of abuse but is not a significant cause of maltreatment. Although empirical findings tend to refute the dependency-stress model (e.g. Benedict, Wulff, & White, 1992; Rindfleisch and Rabb, 1984; Sullivan et al, 1987), and comprehensive ecological models have become accepted as a more robust way to explain high rates of abuse among children with disabilities (Sobsey, 1994), many CPS workers still focus on parent stress and burden.” In fact, empirical findings have confirmed this connection.

⁶⁰⁵ Furthermore, since the multi-factorial issue of causality of disabled child abuse remains undetermined, the answer would not be found through literature. This article only addresses the matter in familial child abuse where it states that the same abusive behaviours reported in institutions where there are child residents are not perceived to be abusive when they occur inside families in private settings.

⁶⁰⁶ The work of Dr. Peter Jaffe comes to mind. It is important to note that there are many different kinds of child maltreatment. See *Report of the Cornwall Inquiry: Phase One: Facts & Findings*, vol 1 (Toronto: The Cornwall Public Inquiry, 2009) online: Cornwall Public Inquiry <http://www.attorneygeneral.jus.gov.on.ca/inquiries/cornwall/en/report/v1_en_pdf/E_Vol1_CH02.pdf>, at Chapter 2, “Expert Evidence on Child Abuse”.

⁶⁰⁷ There is medical model literature that focuses on the psychological stress of caregiving mothers, almost to the exclusion of all else. In it expert advice is proffered on ways for mothers to reduce their own stress. One recent suggestion is meditation. Psychiatry is central to child welfare evaluations and as a field it influences how child welfare measures parental capacity and pathology. This reality, in combination with the current ethos of self-reliance, risk and the responsabilization of caregiving mothers for their own predicaments, I believe is one scenario that is experienced by mothers. See Lunskey, Y., Hastings, R. P. Weiss, J. A., Palucka, A. M., Hutton, S., & White, K. “Comparative Effects of Mindfulness and Support and Information Group Interventions for Parents of Adults with ASD and other Developmental Disabilities” (2017). *The Journal of Autism and Developmental Disorders*, 47:6, 1769.

into an issue of whether or not she is coping and she may be served with a child protection application as a result.

Such mothers may be seen to have internalized ableism, or to have other ‘deficits’. Either way, mothers become the focus of attention, rather than the need to better support complex care. I argue that this myopic approach places disabled children at risk, for example of becoming state wards.

Looking more closely at the backdrop to the debate on burdens of care, which has to do with whether disabled children place stressors on the parent (mother), different views have been held. According to Dick Sobsey, American authors William Friedrich and Jerry Boriskin advanced the dependency-stress hypothesis in relation to the care of disabled children. However, what these two graduate students state in their 1978 article is that, “[w]e are not suggesting that children with defects and disabilities necessarily provoke abuse.”⁶⁰⁸ What they said, as they note, was not initially articulated by them, but by Green⁶⁰⁹ earlier in 1975, and that was that “there are *four* conditions necessary for abuse: a special parent, a special child, a crisis and cultural tolerance for violence.”⁶¹⁰ Enumerating four conditions that can precede abuse of a disabled child by a caregiving parent is not the same thing as stating that there is a straightforward unidirectional cause and effect process respecting maltreatment of children with disabilities by caregiving parents.⁶¹¹ This is an important misconception and misarticulation transposed from child welfare/psychology into critical disability theory. Sobsey states that the dependency/stress

⁶⁰⁸ William Friedrich & Jerry Boriskin, “Primary Prevention of Child Abuse: Focus on the Special Child” (1978) 29:4 *Psychiatric Services* 248 at 251 [Friedrich & Boriskin, “Primary Prevention”].

⁶⁰⁹ F. C. Green, “Child Abuse and Neglect: A Priority Problem for the Private Physician” (1975) 22:2 *Pediatric Clinics of North America* 329.

⁶¹⁰ Friedrich & Boriskin, “Primary Prevention”, *supra* note 608, at 248 might just as likely have prompted an attachment-deficiency model of child abuse as the literature on the prevalence of abuse of low birth weight infants appears as a central theme in their 1976 and 1978 articles.

⁶¹¹ *Ibid.*, along with an earlier article, William Friedrich & Jerry Boriskin “The Role of the Child in Abuse: A Review of the literature” 1976 46:4 *American J Orthopsychiatry* 580. In the latter article Friedrich and Boriskin present a careful review of available research at that time and state “one can only speculate as to cause and effect where there is child abuse”. *Ibid* at 581. They do point to the higher levels of abuse where there are premature infants, and in particular where they have been separated from their mothers at birth in hospital. They also pointed out a relationship between maltreatment and children with intellectual disabilities, commenting that “the complexity of the phenomenon and the large number of interacting variables make any position as to cause and effect most tenuous.” *Ibid* at 586. They observed that “the factors contributing the most weight to the disproportionate retardation associated with abuse will not be readily apparent for some time.” They do use the language of “abuse prone” when describing children with “retardation”. They add however that, “while the association of retardation and abuse is clear-cut, etiological factors remain muddled, and there is a dearth of experimental data...further experimental and clinical attention should be given to the “abuse prone” hypothesis”. *Ibid* at 584. In spite of Friedrich and Boriskin’s statements that their data do not provide an understanding of the cause and effect of maltreatment, Sobsey attributes their efforts with the advancement of the stress dependency model. He set up a straw man, which he then takes down, commenting that this model has explained disabled child maltreatment simplistically [and] appears to be unjustified. Furthermore, the position he advanced has been variously relied upon and referenced extensively without a significant challenge until very recently. See also Jesse J. Helton & Theodore P. Cross, “The relationship of child functioning to parent physical assault: Linear and Curvilinear Models” (2011) 16:2 *Child Maltreatment* 126.

model “was based on assumption and when it was tested, it was not empirically supported. Stress and dependency levels turned out to have little value in predicting abuse.”⁶¹²

Thus, claims have been made that maternal stressors do not matter and claims have been made that care burdens do not exist by conservative strands within critical disability theory. This is so, even in the setting of disabled child maltreatment, where the stakes for disabled children and their mothers are high. Advocates, such as Sobsey and some commentators writing for CCD, see instead eugenic impulses, with the identified cultural tolerance of violence towards disabled children being expressed in private homes at the hands of failed mothers. They do not focus on the broader issue of cultural tolerance of violence, noted by Boriskin and Friedrich as an important feature which some disabled and indeed non-disabled mothers live with as well. A gendered lens on care would have included male violence, which I argue includes the reframing of caregiving mother’s care burdens as personal pathology.

The literature review reveals ideological blind spots in some critical disability research. For example, McConnell et al.⁶¹³ (with researchers Sobsey and Uditsky) report that where the care of disabled children is concerned “heightened levels of maternal and familial distress might be expected” and they refer to maternal depression, anxiety and stress.⁶¹⁴ They conclude “however the *absolute risk* of such negative psychological conditions may not be as high as many people think: a large majority of mothers and families bringing up children with disabilities appear to ‘do well.’”⁶¹⁵ Even though they acknowledge that caregiving mothers are significantly more often depressed and anxious, they do not consider risks *for caregiving mothers*. That is the blind spot. I suggest the reason for it is that they see childhood disability care as unidirectional, rather than relational.⁶¹⁶ In terms of the issue of whether mothers ‘do well’, an article by Carnevale, Alexander, Davis, Rennick and Troni, appears in their end references.⁶¹⁷ This research however found that the lives of parents of children in their study were highly complicated, overwhelming, involved the daily threat of death, and were characterized by financial and other unpredictability as well as instability. This suggests that *absolute risks of all kinds are high to children and parents*. To state they ‘do well’ is inaccurate.

⁶¹² In support of his position, which has been referenced widely, he references Mary I. Benedict, Louise M. Wulff & Roger B. White, “Current Parental Stress in Maltreating and Nonmaltreating Families of Children with Multiple Disabilities” (1992) 16:2 Child Abuse & Neglect 155.

⁶¹³ McConnell et al *supra* note 531

⁶¹⁴ McConnell et al *Ibid* note 531 at 118

⁶¹⁵ McConnell et al *supra* note 531 at 118

⁶¹⁶ In-text McConnell et al reference for their assertion that families ‘do well’ an article by “Carnevale, Alexander, Davis and Rennick”. Perhaps they intended to reference R.J Earle, J.E Rennick and F.A Carnevale “‘It’s O.K., It Helps Me To Breathe’: The Experiences of Home Ventillation From a Child’s Perspevctive” (2006) 10:4 Journal of Child Health Care 270 -82.

⁶¹⁷ Carnevale, Alexander, Davis, Rennick and Troni *supra* note 360. The conclusion of McConnell et al appears at at 118 of their Report.

The fear of socially conservative child disability rights advocates appears to be that acknowledging heavy burdens involved in caring for severely disabled children condones disability discrimination, or that it will condone and perpetuate negative conceptions of disabled people. It does not. Rationalizing care stressors and heavy care costs through the blanket denial of burdens, minimizing their import and silencing overextended support-seeking caregiving mothers are attempts to downplay very serious concerns. To do this is to engage intellectually in what psychoanalysts refer to as splitting. Having self-consciously deployed my own reflexivity on this deeply troubling issue, I note that the word ‘splitting’ has been applied to describe an inability to assimilate positive and negative aspects into a single coherent perspective.⁶¹⁸ Splitting has also been explained as a psychological defense mechanism, and as such, something that takes place unconsciously.

Mothers of all stripes have been subjected to a great deal of “all or nothing” thinking by others, and are being subjected to it by socially conservative strands in critical disability theory as well. In denouncing the dependency-stress model of abuse, Sobsey⁶¹⁹ and Scorgie and Sobsey⁶²⁰ set up a straw man I assume so that they can knock it down, in a manner they believe will serve the advancement of disability rights.

Further on the subject of splitting, social model of disability research from the University of Alberta over the past 15 years has devoted itself to pathologizing heavy burdens of care as comprising individual caregiver failure.⁶²¹ This research uses the term ‘good copers’ to describe mothers primarily. These are mothers who meet the criteria of appropriate ‘family adjustment’ and child well-being by referring agencies.⁶²² By inference there are likewise bad copers. The other framing that appears in this research is caregiver incompetency.⁶²³ An isolated, lonely caregiving mother with a severely disabled child is described as an example of a parent having allowed disability to take over her life, and as such, lacking in resilience.⁶²⁴ It is curious that some of the same disability theorists who criticize child welfare for constructing the disabled child as “stress”⁶²⁵ construct caregiving mothers in exactly the same manner. Some disability theorists inadvertently join ranks with child welfare in placing responsibility for the

⁶¹⁸ Melanie Klein refers to the good mother and the wicked stepmother of children’s stories. Otto Fenichel, *The Psychoanalytic Theory of Neurosis* (New York: Routledge, 1997) at 157.

⁶¹⁹ Sobsey, “Exceptionality”, *supra* note 601.

⁶²⁰ Scorgie & Sobsey, *supra* note 160.

⁶²¹ See e.g. Scorgie & Sobsey, *supra* note 160; McConnell et al, “Fabric of Everyday Life”, *supra* note 531; and McConnell, David, et al, “Benefit-Finding or Finding Benefits? The Positive Impact of having a Disabled Child” (2015) 30:1 Disability & Society 29 [McConnell, et al, “Benefit-Finding”].

⁶²² See Scorgie & Sobsey, *supra* note 160 at 198.

⁶²³ See McConnell et al, “Fabric of Everyday Life”, *supra* note 531

⁶²⁴ *Ibid* at 84 and 89

⁶²⁵ See e.g. Sobsey, *Children with Disabilities*, *supra* note 594.

challenges posed by support of disabled children at their mother's feet.⁶²⁶ It is time to move beyond demonizing caregiving mothers to embrace the realities of maternally complex care, which has as its focus best interests of the disabled child.

Some researchers adopting the social model of disability in their research characterize parents of disabled children as "predisposed" to report care burdens.⁶²⁷ They add that the difficulties parents report are inappropriately emphasized in literature and research. Thus, those writing the research reports are also faulted for reporting what they hear from caregiving parents. The socially conservative social model proponents argue that any focus on challenges experienced by those parents providing care is unhelpful, stating, "some researchers have suggested that a negative emphasis is misleading, not factually supported and is even potentially dangerous."⁶²⁸

To reiterate, the aim of social model of disability proponents appears directed at shutting down the conversation respecting burdens encountered in (primarily) maternal care. In this way, some proponents dangerously undermine the aims of disabled children's mothers. It is also apparent that the aim of these advocates is to redirect the discussion towards the benefits of parenting a disabled child, which is an entirely different conversation and not the one that advocating mothers seek to remedy. Socially conservative strands in disability rights are fond of claiming that the experience of having a disabled child leads to a positive personal transformation in parents, as something that makes them better people.⁶²⁹ Thus the primary focus of their research is on the benefits that disabled children confer on parents. However, I agree with Knight, an Australian academic and mother of a child with an intellectual disability, who asserts that the view "that higher psychic rewards are delivered to mothers whose experiences are the most difficult has a disturbingly patronizing edge."⁶³⁰ Harold Kushner agrees, stating, "I am offended by those who suggest that God creates retarded children so that those around them will learn compassion and gratitude."⁶³¹ These conversations must not be permitted to redirect a line of inquiry

⁶²⁶ Bill Bevan, a former Executive Director of the Windsor-Essex Children's Aid Society, in a news report discussing child welfare's insistence that severely disabled children be placed into state care when mothers become overwhelmed by their care needs stated "By the time they get to the children's aid society, they're saying I cannot cope...when you get to the point *where you're not coping well* and you feel so stressed that you're not able to manage this child with such behaviour, that puts a child at risk." Mother Jennifer Bray, interviewed in this same article simply needed support, and stated that she felt "violated" having to relinquish custody of her son Wesley to the Windsor CAS. Craig Pearson, "Parents of Disabled Kids Win Support: Minister Reissues order to CAS", *The Windsor Star* (9 May 2005) A1 [Pearson, "Parents of Disabled Kids"]. (author emphasis).

⁶²⁷ See McConnell et al, "Benefit-Finding", *supra* note 621.

⁶²⁸ Scorgie & Sobsey, *supra* note 160 at 196. Dangerous to whom, one is inclined to ask.

⁶²⁹ See *ibid*.

⁶³⁰ Knight, *supra* note 259 at 666. She refers to Hastings and Trute for advancing views in the literature that challenging experiences with disabled children offer parents personal growth opportunities. I would argue this is not a human rights approach at all.

⁶³¹ Harold S. Kushner, *When Bad Things Happen to Good People* (New York: Random House, 1981) at 35.

that caregiving mothers pose, which is what should the support rights of mothers with severely disabled children be?

On the positive side, initiatives in the social model of disability scholarship generally (regardless of political leanings - which I believe are at the heart of this discussion) are geared towards bringing about attitudinal changes in society towards disabled children, to end stigmatizing practices and to further inclusion. In keeping with this, the claim is made that having a disabled child is good for one's health and spirit, and impacts one's quality of life favourably.⁶³² Such approaches assert the innate positive value of the disabled child.⁶³³

Nevertheless, the notion that emanates from critical disability discourse that carers and therefore caregiving parents are "predisposed" to report burdens can be seen as an attempt to take agency away from those who make claims that they experience burdens, namely caregiving mothers.⁶³⁴ The suggestion is that these mothers' claims to need support lack authenticity, or are otherwise suspect. In fact, parents report burdens of care at different points in time, *regardless* of disability/non-disabled status of their children. This is a transplantation of long-standing social model critiques of public arms-length (institutional) caregiving relationships as oppressive into what are fundamentally private and intimate supportive maternal-child relationships. For mothers this can be interpreted as an attempt to end the discussion of burdens, which is a line of inquiry that is seen to threaten the hard won autonomy of disabled people. However, no comparisons can realistically be drawn between care providers in institutional settings, where there were profound structural forms of institutional oppression, and mothers who perform care in the private sphere. The argument that there are power inequities between mothers and their disabled children is likewise not applicable, because there are power differentials between all parents and all children.⁶³⁵ If properly exercised, this power is used to advance children's best interests.⁶³⁶ This is all the more the case with respect to a severely disabled child, heavily reliant on his or her mother's care, in ways a typical child is not. Rosemarie Garland Thomson's discussion of the debates within the disability community pertaining to the asymmetry in carer and care-receiver relationships, and the problematic implications of that in terms of power dynamics likewise has no application to mothers. Garland Thomson comments that circumstances of disability itself require interdependency, not asymmetry, and she explains that the need of assistance must be included in conversations about rights. I

⁶³² *Ibid.*

⁶³³ Michael Oliver, whose work is centered in the social model of disability, devoted only 6 pages of his book to children with disabilities. Oliver & Sapey, *supra* note 579.

⁶³⁴ Susan Wendell argues that critical disability studies have privileged the views of the healthy disabled in "Unhealthy Disabled: Treating Chronic Illness as Disability" (2001) 16:4 *Hypatia* 17 at 22-23. This may explain the missing experiences of the support needs mothers with *severely* disabled children.

⁶³⁵ See Amy Curtis Bastida, *Maltreatment Prevention Groups for Developmental Disabilities: A Clinician Manual* (Doctoral Dissertation, Pepperdine University, 2007) [unpublished].

⁶³⁶ In fact, it is a parent's legal duty to be in charge of their 'charge'.

agree. However, where caregiving mothers are concerned, asymmetry is, as noted already, built into the relationship. For example, children are not legally independent.⁶³⁷ Where there are children with severe disabilities, that asymmetry may be extreme.⁶³⁸

Interestingly, Martha Fineman⁶³⁹ has argued that in present legal conceptualizations, mothers are assumed to be in an adversarial position to their children, something that may also cast a shadow over how mothers' complaints about burdens are viewed.⁶⁴⁰ The presumption of an adversarial relationship existing between caregiving mother and severely disabled child is highly prejudicial. Research finding that caring for disabled children *confers benefits* on caregiver (parent) needs to be examined closely.⁶⁴¹ Mothers know intimately what the benefits of *mothering* disabled children are. Why must we keep funding research to examine what is already a given? That such research gets funded should be no surprise; idealization of maternally complex care fits neatly with the state's own representations of care for the disabled and those who are to provide it. This idealization or myth has to do with mothers, ableism, and gender.

Conceptions of ideal motherhood and disability

American feminist legal scholar Dorothy Roberts, alternately theorizing mothers, racism, and gender, argues that since the ideal mother is white, the black mother is devalued. She is thus perceived as undeserving.⁶⁴² In a similar vein, since the ideal mother has non-disabled children, socially conservative approaches to disability care, meshing as they do with the interests of the privatizing state, seek to construct the ideal mother as one willing to collapse her identity into that of the generic caregiver. When she refuses, such as when she makes demands for support upon the state, she is seen to exaggerate her needs. On that basis, she must be ignored or pathologized. However, the Canadian legal databases reveal that caregiving mothers are unwilling to accept this construction of who they are and what they do. Rather than accepting it, they have chosen to litigate to try to get the support they and their disabled children

⁶³⁷ They cannot sue on their own, and they are governed by a separate legal regime. They must be in someone's legal custody until age of majority and that person must protect them.

⁶³⁸ Likewise, as noted, Anita Silvers provides commentary on the valorization of the perspective of caregivers *at the expense of* the recipients of care. See Garland-Thomson, "Integrating Disability", *supra* note 254.

⁶³⁹ Fineman, *The Neutered Mother*, *supra* note 271.

⁶⁴⁰ Jane Murphy points to areas where courts have looked at the mother's conduct and tied it to a failure to meet the best interests of her child. Areas she examines include adultery, woman abuse, lesbian, mental fitness, and alternative lifestyles. Jane Murphy, "Legal Images of Motherhood: Conflicting Definitions from Welfare Reform, Family and Criminal Law" (1998) 83:3 Cornell L Rev 742 online: <<http://scholarship.law.cornell.edu/cgi/viewcontent.cgi?article=2722&context=clr>>.

⁶⁴¹ See e.g. McConnell et al, "Benefit-Finding", *supra* note 621. The question the title asks, "Benefit-Finding or Finding Benefits?"

⁶⁴² Roberts, "Racism and Patriarchy", *supra* note 219 at 14.

need. However, as will be seen in subsequent chapters, the idealization of mothers with disabled children makes its way into the text of legal decisions, and it is for this reason that such myths must be exposed.

Confronting the Uncomfortable Truths

It is a difficult reality that the care required for severely disabled children is not only onerous, but that it can also be costly. This truth must be confronted before mothers and their severely disabled children's legal rights to support can be met. Social workers in child welfare jurisdictions are faced with these realities, however critical disability theorists writing on social work have tended to focus on disabled child maltreatment.⁶⁴³ That is one uncomfortable truth, but only one of many.

Those who claim that there are not significant burdens of care in respect of children with severe disabilities fail to appreciate the extent to which gender discrimination is bound to disability discrimination.⁶⁴⁴ This failure to appreciate is an enactment of Freire's culture of silence. Historically, many disability rights advocates advising on childhood disability policy across Canada have been white, middle-class career-men. Where this is the case advice on care policy has been given by those with 'care-privilege'.⁶⁴⁵ That is to say by individuals who have not had primary responsibility for complex forms of care in the conglomerate assigned to them socially.⁶⁴⁶ Meanwhile legal advocacy concerning policy in this area is largely undertaken mostly by women (mothers). And although Canadian society, like many other societies, deems the care of severely disabled children to be women's work,⁶⁴⁷ mothers have been reprimanded for providing their opinions. At least as far back as 1973, female disability advocates who were also mothers complained about male disability advocates' efforts to censure their views.⁶⁴⁸ Audrey Cole, who last year on behalf of her son brought an important disability case at the Ontario Human Rights Commission, reported to a disability studies professor, Melanie Panitch, that in the early days of the movement, male leaders in the Association for the Mentally Retarded told her she was obsessed with law and order, as if that was a bad thing. Apparently, for the mother of a severely disabled child, it was. In her presentation on litigating against "the Deaf Irish State", Anna Kingston argues that what litigating

⁶⁴³ See e.g. Oliver & Sapey, *supra* note 579. Only a few pages of this important book are devoted to the needs of disabled children. Their primary need in my view being that their caregiving mother is adequately supported.

⁶⁴⁴ I analogize this situation to what Cossman states about gender. She states that stories about gender are not only about gender *per se*, because the stories also involve class and race. She states we assume white and middle class in our thinking about gender. See Brenda Cossman. "A Matter of Difference: Domestic Contracts and Gender Equality" (1990) 28:2 Osgoode Hall LJ 303 at 306. At least that was true in 1990 when she wrote this. I add to her comment that stories about gender also implicate disability.

⁶⁴⁵ I have come up with this term for use in relation to the problems of caregiving mothers with severely disabled children and support.

⁶⁴⁶ See Katherine Runswick-Cole, "'The Tribunal Was the Most Stressful Thing: More Stressful than My Son's Diagnosis or Behaviour': The Experiences of Families Who Go to the Special Educational Needs and Disability Tribunal (SENDiT)" (2007) 22:3 Disability & Society 315 at 322. It is primarily mothers at the Tribunal.

⁶⁴⁷ See Hilary Stace. "Disability Care as Women's Work" (2013) 27:1 Women's Studies Journal 13 at 13.

⁶⁴⁸ See Panitch, *Accidental Activists* (Book), *supra* note 153.

caregiving mothers say is filtered through ears deaf to mothers. The night-watchman state⁶⁴⁹ also silences mothers of disabled children, refusing to hear their demands. One example of this can be heard in Ontario former MPP, mother of a disabled son, Ontario's first patient ombudsman, and now Provincial Minister of Health Christine Elliot's past many demands of the province to strike a select committee to examine supports for parents caring for disabled adult children at home. In her plea to parliament to get on with the business of striking this committee, Elliot said "Mr. Speaker, The Minister and members of this government cannot continue to hide behind this charade."⁶⁵⁰

The caregiver critique emanating from critical disability studies and the state's refusal to "hear" about burdens of care and need of support compound the burdens that caregiving mothers already shoulder. The culture of silence and censure adds to the challenges mothers face when trying to advance their right to support. However, as I argue, caregiving mothers, immersed as they are in complex forms of oppression "can identify the special garb worn by cultural silence in society, to use Freire's own language."⁶⁵¹ The garb is denial of the work complex forms of care entails.

As noted above, prior to the advent of the social model of disability, the medical model held sway, characterizing the disabled child as being a burden. Although the notion of the disabled child as a burden has been largely eroded⁶⁵² for a quarter of a century,⁶⁵³ and although it has been made clear in the literature from the early 1990s onwards that what actually burdens mothers is a lack of support, some disability scholars persist in portraying mothers and the professionals who work with them who also claim there are burdens, as blaming the child for their disability and the care the child requires.⁶⁵⁴ Labeling mothers as ableist actors is another silencing tactic. I argue that this is partially the strategy of a political agenda which aims to make disability and medical care, no matter how onerous or how distressing, something to be provided by mothers. It has been pointed out that advancing the rights of the

⁶⁴⁹ See Sawyer, *supra* note 278.

⁶⁵⁰ Christine Elliott, "Christine Elliott Demands Answers for Select Committee Delay" (19 September 2013) online: YouTube <<https://www.youtube.com/watch?v=iFD4-szRW34>>. She later posted the ensuing *Select Committee on Developmental Services Interim Report* (Toronto: Legislative Assembly of Toronto, 2014) online: <http://www.ontla.on.ca/committee-proceedings/committee-reports/files_html/INTERIMREPORTENG-Final.htm> [*Select Committee, Interim Report*], to her website.

⁶⁵¹ Freire [Education] *supra* note 133 at ix.

⁶⁵² The notion of the disabled child as a burden has been retained in immigration policy in Canada however. It has long been a basis upon which Citizenship and Immigration could refuse admissibility of disabled children, with the government view being that disabled children's needs place excessive demand of the health and social service system. See the newsreport "Disabled Child Immigration Decision Reserved" *CBC News* (23 Feb 2010) online: *CBC News*, <<http://www.cbc.ca/news/canada/montreal/disabled-child-immigration-decision-reserved-1.901172>>. Since I stopped conducting research, I have learned that this issue is now being reviewed.

⁶⁵³ See Maureen O. Marcenko & Judith C. Meyers, "Mothers of Children with Developmental Disabilities: Who Shares the Burden?" (1991) 40:2 *Family Relations* 186, stated that it was not realistic to expect women continue in the role of primary caregivers to disabled children as a direct result of the inevitable 'personal sacrifice' this would entail without their obtaining services and supports. See also the work of Sarah Green, *supra* note 461, which likewise addresses "burdens" to mothers as not being the child or the child's disability.

⁶⁵⁴ For discussions of this phenomenon see McLaughlin, *supra* note 246; and Priestly, *supra* note 443.

child has been done at the expense of their mothers.⁶⁵⁵ It also has to be pointed out that mothers of disabled children experience forms of maternal oppression *in different ways* than do the mothers of children who do not have disabilities.⁶⁵⁶ Thus it is not simply “mother’s rights” that are the problem. The situation is more complex than that alone would suggest.

The failure to recognize unique burdens of care and address them openly in the above-noted research places disabled children at risk of harm inside families and moreover, at risk of institutionalization.⁶⁵⁷ These are the very things those enamoured of the social model of disability claim to be concerned about.⁶⁵⁸ For example, the answer to the research question posed by McConnell et al, “What factors influence family attitudes towards out of home placement?” was in part, “Parents are unlikely ever to consider placement as an option for their disabled child if their daily routine is fitted to the local ecology and family resource-base, and congruent with their values and goals, and with the needs, interests and competences of individual family members.”⁶⁵⁹ This statement flies directly in the face of what family law litigation, social benefit litigation and child welfare litigation cases tell us, which is that even *well-resourced, dedicated and highly competent* mothers require more support than they get. This statement also flies in the face of what the Ontario Ombudsman found in his investigations into custody loss and placement of children with disabilities in Ontario.

The situation of Kristine Gravel McKeague in Ottawa also illustrates the error in the McConnell et al research finding. McKeague was a well-resourced infant massage therapist, social service worker, home birth advocate, disability advocate and experienced mother, in an intact middle-class marriage with an involved spouse. She sought out-of-home placement for her severely disabled daughter and had to go to the press to get it because Ontario refused to provide it unless she relinquished custody of her baby girl. Many caregiving mothers have no resource base whatsoever, or have only a narrow one. For these mothers, the reality is that out-of-home placement remains their only option *unless services and supports are made available to prevent it*. Burdens of care cannot be explained away or silenced through women-blaming discourses or general references to a mother’s ecology and resource bases.

Conclusions such as the one that ‘parents’ will not consider placement for disabled children if their daily routine is fitted to the local ecology and family resource-base, and congruent with their values and goals, and with the needs, interests and competences of individual family members, qualifies by

⁶⁵⁵ See Chesler, *supra*, note 23.

⁶⁵⁶ See Roberts, “Racism and Patriarchy”, *supra* note 219. I draw from her idea that African American mothers experience oppression differently given the presence of racism.

⁶⁵⁷ Breen, *supra* note 340 at 18, argues that childhood disability remains institutionalized, albeit in the family under current policy approaches.

⁶⁵⁸ McConnell et al, “Fabric of Everyday Life”, *supra* note 531, seek answers to three questions. No research can find that “parents are unlikely ever to consider” anything.

⁶⁵⁹ *Ibid* at 12.

definition as ‘conservative pressure’. After all, whose “daily routine” are they referring to? Not a single or divorced mother surely. On a positive note, conservative pressure, such as the above comments, can be seen as forming part of a dialect in tension with the process of consciousness-raising, as described by Montero.⁶⁶⁰

To close the discussion of caregiving mothers in the social model of disability, attention must be drawn to a final irony. It is that the disability rights movement chose the slogan “Nothing about us without us” but seems not to appreciate, when dealing with caregiving mothers’ claims to support, that “Nothing about us without us” is a two-way street. The interests and perspectives of caregiving mothers matter a great deal in policy discussions because it is they who perform the majority of care. The social model is limited because it seeks primarily to articulate avenues to autonomy of disabled persons. Considering the support needs of caregiving mothers as integral to improving the lives of disabled persons troubles this endeavour, an endeavour founded on a masculine ideal of autonomy, itself an unsuitable vehicle for the advancement of the rights of the severely disabled child. More than merely limited however, the social model of disability is violent in its articulation and expression. It is to the issue of violence that this review now turns. This is particularly poignant in that disability rights advocacy has likewise focused on institutional violence in the past.

Violence in Models of Disability

Above, I have argued that the medical model of disability, against which the social model came into being, has started to evolve and transform. I have described too the charity model of disability, as one relying on the philanthropic private support of disability, and a problem for caregiving mothers themselves in need of support. I also critiqued the social model of disability in the context of maternally complex burdens of care. In this section, I ready the reader for a fourth approach, which is a model of care capable of accounting for burdens borne by mothers with severely disabled children in domains where they lack rights to support. Here, I argue that expectations placed on mothers that arise in the charity model and conservative threads in the social model share a socially violent streak, in particular for modest, low or no income families, and sole-support mothers with disabled children. It is violent to place social expectations on mothers to provide onerous forms of care without also providing a salary, pension, time off, the ability to save money, and health benefits. It is emotionally and socially violent to siblings of severely disabled children, who are deprived of adequate time and attention from their caregiving mother or who may worry constantly about their family members. These latter features are the underbelly of care. Iris Young and Paolo Freire both describe violence as an aspect of oppression. Freire believed all relationships of exploitation, domination, oppression, “whether or not violence is expressed by drastic

⁶⁶⁰ See discussions in Montero, *supra*, note 130.

means” to be violent.⁶⁶¹ In this vein, it is apparent that violence against mothers with disabled children takes many forms, and I have already mentioned some of them. Another form may be witnessed where mothers seek support through public and private law, as I describe below. I have already addressed that when mothers do not live up to extraordinary expectations, mother-blame takes place, which is a form of social violence.⁶⁶²

Violence has been conceptualized in a variety of different ways and occurs in a various ways. If the lens through which a disability advocate views the world is a eugenic one, centered on the belief that non-disabled people want disabled people dead, that belief colours their interpretation of events respecting mothers with disabled children.⁶⁶³ It is violent to accuse a sole-support mother of wanting her disabled child dead. If beliefs are socially conservative, such that mothers must be the ones to provide full-time care, that, too, colours interpretation of expectations of support and interpretations of tragic outcomes involving mothers with disabled children. Requiring one gender to provide all of the disability care is oppressive, and oppression is a form of violence. The mix of these two belief systems, eugenicism and social conservatism, creates a hostile environment for women who have severely disabled children *and* who have unmet requirements for state supports.

In discussing the 1999 death of an autistic child in his under-resourced, overwhelmed, and depressed lone mother’s full-time care, a commentator writing for the Council of Canadians with Disabilities (CCD) accused Danielle Blais of *wanting* her six-year old son, Charles, dead.⁶⁶⁴ This subjective view then becomes conflated with criminal standards having been satisfied, when they have not. In writing about the Blais case, Joe Woodward concluded that, “The Canadian legal establishment...has apparently given up on Aristotelian theories of justice.”⁶⁶⁵ Upon killing her disabled son Charles, and slashing both of her wrists in a suicide attempt, Blais was charged with first-degree murder, arrested, and put in prison, pending her trial. Initially, the Crown sought a three-year term of

⁶⁶¹ Young refers to violence as involving attacks. I include other forms of institutional violence, including economic, emotional and relational violence in my analysis. Freire, *Education*, *supra* note 133 at 17 n 9.

⁶⁶² See Llina Singh, “Doing Their Jobs: Mothering with Ritalin in a Culture of Mother-Blame” (2004) 59:6 *Social science and Medicine* 1193; Blum, *supra* note 382; Natalie C. Boero, “Fat Kids, Working Moms, and the Epidemic of Obesity Race, Class, and Mother-Blame” in Esther Rothblum & Sondra Solovay eds, *The Fat Studies Reader* (New York: New York University Press, 2010) 113; Paula Caplan, “Don’t Blame Mother: Then and Now” in Margaret Helen Hobbs & Carla Rice eds, *Gender and Women’s Studies in Canada: Critical Terrain* (Toronto: Women’s Press, Canadian Scholars Press, 2013) 99. Caplan calls on feminism to make myths about mothering a priority.

⁶⁶³ *Not Dead Yet* is the name of a disability advocacy organization which has published in the area of disability and children.

⁶⁶⁴ See “The Toll Mounts: Another Child Killed”, (26 March 2001) online: Council of Canadians with Disabilities <<http://www.ccdonline.ca/en/humanrights/endoflife/latimer/2001/03>> [Council of Canadians with Disabilities, “The Toll Mounts”]. This is a violent allegation.

⁶⁶⁵ Joe Woodard, “We feel your not-criminally responsible pain: compassion is overwhelming retribution in Canadian trial law [Danielle Blais case, Robert Latimer case and the Anthony Wischen case]” (1997) 8:48 *British Columbia* 22 (Retrieved from Proquest).

incarceration, to “indicate the lives of the handicapped are just as valuable as the lives of others.”⁶⁶⁶ The issue of disability rights was not ignored in the proceedings. Blais was evaluated by three psychiatrists, who decided that she was psychiatrically disabled. The court ordered that after her suspended sentence ended, Blais was to attend at a treatment centre to be followed by three years of probation during which she had to meet with psychiatrists and a psychologist on a regular basis.⁶⁶⁷ Nevertheless, some members of the disability community perceived Blais to have “gotten away with” killing her young son and were angry that she was not found guilty of murder. No one talked about Blais’s lack of support. The salient point is that without the required support that both mother and son needed and that no one wanted to know about, their relationship ended, and it did so tragically.

Disability advocates who argue that caregiving mothers wish their children dead, do so echoing the thought of Bruno Bettelheim, whose discredited interpretations of mothering disabled children still cast a dark shadow in discussions of mothers of disabled children. Bettelheim held bizarre beliefs respecting the “mother’s wish that her child did not exist.”⁶⁶⁸ In the aftermath of the drowning of six year-old Charles by his mother, Danielle Blais, a CCD advocate wrote that the unmet service needs of disabled people were always an issue, “a very important issue for the living. However, we must be very vigilant when we relate that issue to the murder of people with disabilities, such as Latimer, Wilkieson, Blais, or Baker, *that we do not allow the possibility of anyone misunderstanding the need for services as justifying the murder in any way or degree.*”⁶⁶⁹ A more useful approach is to examine cases where care has broken down, rather than at the point where parent capacity has sunk too low, and then determine what supports would have made a difference. In the Blais’ case, the Catholic ‘special needs’ school Charles attended, the Quebec social service system (on whom public criticism also fell) and the Quebec Autism Society were aware that Danielle needed much higher levels of support. A comment incongruent with the tenor of

⁶⁶⁶ “Mother’s Jail Term Suspended for Drowning Son” *Star-Phoenix [Saskatoon]* (3 July 1997) A10. Retrieved from Proquest.

⁶⁶⁷ *Ibid.*

⁶⁶⁸ Bruno Bettelheim, *The Empty Fortress: Infantile Autism and the Birth of the Self* (New York: The Free Press, 1967) at 125.

⁶⁶⁹ See Council of Canadians with Disabilities, “The Toll Mounts”, *supra* note ##. In 2011, an American psychiatrist, author, and mother with a disabled son was in a murder suicide instigated by her. Her sister stated to the press “It’s very hard being a single parent under any circumstances, but to have a high-needs child is overwhelming.” In court documents, psychiatrist Joyce Braak, and Ben’s godmother, stated she “could not have a more superb mother than Margaret Jensvold” and Bob Baum, a lawyer acting for the mother in a dispute to get him better special education stated part of her commitment was how strongly she delved into her son’s medical problems. Arline Kaplan, “Psychiatrist Kills Son, Commits Suicide” *Psychiatric Times* (11 April 2011) online: <<http://www.psychiatrictimes.com/articles/psychiatrist-kills-son-commits-suicide>>. See also “Mother Who Killed Her Three Disabled Children Overwhelmed with Care, Court Rules” *The Guardian* (18 November 2014) online: <<http://www.theguardian.com/uk-news/2014/nov/18/tania-clarence-hospital-order-sentence-killed-three-disabled-children>>; and “Tania Clarence Sentenced for Children’s Manslaughter” *BBC News* (18 November 2014) online: <<http://www.bbc.com/news/uk-england-30096820>>.

the rest of this damning piece by CCD is that “CCD’s member organization COPHAN⁶⁷⁰ informed the Quebec government a year ago that it was putting children with disabilities at risk.”⁶⁷¹

Quebec disability advocates seemed to have had no difficulty connecting the dots between supports and maternal-disabled-child wellbeing. However, little seems to have changed. In 2003, four years after the death of Charles Blais and his mother’s attempted suicide, a Montreal newspaper reported on Michele Drapeau, another desperate caregiving mother. She was interviewed about the two-year wait for her severely disabled son to receive provincial care. His physicians agreed he was too disabled to be cared for by her at home, and that his being placed in a hospital was an unacceptable alternative, but necessary under the circumstances. Drapeau is quoted as stating, “We don’t know where to turn ... Did they think it was humanly possible to stay up all day and all night caring for someone?” adding that Quebec paid out \$300 for her son’s homecare.⁶⁷² Her case stands as an example of a woman’s life without a right to disability care and support.

In CCD online discussions concerning the death of Charles Blais, there was no focus on the fact that his father had abandoned him. There is no corresponding discourse of father-blame in the setting of childhood disability care, except in the notorious *Latimer* case, in which Robert Latimer killed his disabled daughter, Tracy.⁶⁷³ The missing father played a role in Charles Blais’s death that ultra conservative organizations such as *Fathers For Life* chose not to explore with the same vitriol in their condemnation of Danielle Blais.⁶⁷⁴

Psychiatrist and neurologist Mark Palermo states that in the setting of the murders of children with autism, what he calls the “normal” stress in looking after a child is enhanced knowing that there may be little change in behaviours and by the difficulties of raising a disabled child, and, he asserts “*by the not insignificant fact that child care personnel willing to care for an autistic child are hard to find.*”⁶⁷⁵ For many mothers costs of care are a significant issue. Palermo’s views do not accord with those of socially conservative disability rights advocates. Regarding CCD, which is the voice of Canadian disability rights advocate, the Disabled Women’s Network of Canada once stated, “we find ourselves at odds with this

⁶⁷⁰ La Confédération des organismes de personnes handicapées du Québec.

⁶⁷¹ “Charles Blais, 6, Murdered by Mother” (13 November 1996) online: Council of Canadians with Disabilities <<http://www.ccdonline.ca/en/humanrights/endoflife/latimer/1996/11c>>. The rhetoric does not match what was known to be taking place by concerned Quebec advocates.

⁶⁷² Catherine Solyom, “Severely Disabled Children in Limbo” *The Gazette* (5 April 2003) A6.

⁶⁷³ *R v Latimer*, 2001 SCC 1, [2001] 1 SCR 3.

⁶⁷⁴ See Walter H. Schneider, “Two Brands of Compassion, Outrage and Justice” (30 November 1998) online: Fathers For Life <http://fathersforlife.org/fv/outrage_compassion_justice.htm>.

⁶⁷⁵ Mark T. Palermo, “Preventing Filicide in Families with Autistic Children” (2003) 47:1 *Intl J Offender Therapy & Comparative Criminology* 47 at 53. His statement does not apply to all autistic children of course and the issue may be that qualified kind caregivers may be hard to find and too expensive for mothers to pay.

very patriarchal model of a group ... Discrimination against and ignorance of feminist principles is systemic and I think we must continue to fight where it is necessary.”⁶⁷⁶

Clearly the intersection of gender and disability demands greater attention. The ground on which to fight is that of interpretation of what is clearly being understood outside and inside the disability community as being women’s work.

I conclude this section with the comment that the charity and social model approaches to care support for disabled children do the same thing, but in different ways. In keeping with what Knight insightfully articulated, both models represent disabled children as “intrinsically more valuable” than non-disabled children and do so in “a self-conscious conversation of socio-cultural messages to the contrary.”⁶⁷⁷ However, where the charity model places mothers with disabled children on a pedestal, the social model shoves these mothers off it. Both approaches are emblematic of status misrecognition. In order to move past misrecognition to recognition, there needs to be a fulsome comprehension in law and policy of the entire range of care burdens. This can only be arrived at through a model of childhood disability that is fully inclusive of mothers, with a view to their co-existing legal right to support. It is to this model, which is a model of maternally complex care, which I now turn.

The Combined Approach – A Relational and Non-Adversarial Model of Care

The combined approach to understanding care in the setting of severe disability in childhood is both contextual and relational. The relational aspect distinguishes it from other approaches. It includes aspects of the social and medical models of disability, but also accounts for mothers’ embodied and other experiences of providing care.⁶⁷⁸

After discussing the combined approach, I examine the Supreme Court of Canada litigation in *Eve*, which sheds light on reasons why a new approach is required to situate the support needs of mothers with severely disabled children who state they do not want to provide care beyond a certain point. Critiques of *Eve* include the absence of a relational approach in the application of law to the support needs of Mrs. E. and Eve. Examining disability through intersecting statuses and reviewing qualitative research

⁶⁷⁶ Lisa Vanhala. “Disability Rights Activists in the Supreme Court of Canada: Legal Mobilization Theory and Accommodating Social Movements” (2009). 42:4 *Canadian Journal of Political Science / Revue canadienne de science politique*, 481 at 996-997.

⁶⁷⁷ Knight, *supra* note 259 at 667

⁶⁷⁸ See Green, Darling & Wilbers, *supra* note 397 at 160, state that neither the medical nor the social model of disability properly describe the experience of parents of children with impairments. They refer to the feature of embodiment as one reason why not. Monsen, *supra* note 190 at 160, describes the mothers of children with spina bifida as “living worried.” Part of living worried was living exhausted. It has been scientifically shown that the effects of heavy care alter mother’s DNA. See Epel et al, *supra* note ##. In other research, Joerd J. Ebisch et al, “Mother Child Synchrony: Thermal Facial Imprinting of Autonomic Contagion” (2012) 89 *Biological Psychology* 123 at 127, it was found that a child’s experience of distress “induced significant emotional arousal mediated by the autonomic nervous system” of the mother that were “surprisingly similar” to those in her child.

from over the past fifty years, Green, Darling & Wilbers suggest that a combined approach is required to fully account for the needs of mothers with disabled children. Mothers, they point out, especially those whose children have complex health care needs, do not reside in the realm of theory, but rather in medical and other milieus. In their research, mothers were found to draw on the medical *and* social models in their development of ‘counternarratives’ to societies’ perceptions of them and their children.⁶⁷⁹ These counternarratives have been in existence for some time. Margaret Newman, mentioned previously, quotes from an interview with the mother of a disabled child who died, who reported that the death was a “very profound experience and changed my life dramatically.”⁶⁸⁰ The mother stated that this experience changed how she related to others and her understanding of the world. She says it best when she remarks, “what happened to me was a very deep, very intimate, very powerful experience”⁶⁸¹ This remark challenges the tragedy presentation critical disability theorists state has dominated discussions during the period that the interview occurred. It does so by introducing the as yet under-examined existential aspect to maternally complex care, which is much more powerful than a narrow “tragedy” lens. The practice of drawing on established models of disability by offering different explanations in their development of counternarratives is indicative of mothers problematizing their experiences in relation to medicine, culture, and disability theory based on experience.⁶⁸² In so doing, they arrive at new narratives, based on their knowledge, something that also supports standpoint theory’s claim that a feminist epistemology comes from somewhere specific.

Green points out that historically, mainstream scholarship has focused on emotional burdens, observing that it has disregarded “burdens imposed by negative public attitudes toward disability and inadequate support for the expensive and time-consuming task of caring for a child with special needs.”⁶⁸³ To deal with the complexities presented by care, in her combined approach Green breaks burdens down into those subjective and objective. Objective burdens include stress that is related to the care of the child, as well as financial problems, the lower ability to pursue friendships, and high energy spent seeking services.⁶⁸⁴ A major finding in joint research by Green, Darling & Wilbers was that mothers state they are

⁶⁷⁹ Green, Darling & Wilbers, *supra* note 397 at 155.

⁶⁸⁰ Newman, *supra* note 151

⁶⁸¹ Newman, *supra* note 151 at 128.

⁶⁸² See Fisher & Goodley, *supra* note 192. Fisher and Goodley explain that the phrase “philosophy of the present” was drawn from other scholars, Davies and Ezzy, who describe liberation from a life with uncertainty and the need to struggle for a future, as being a form of freedom to live in the present. I find this is an accurate and insightful observation in the setting of mothering children with severe disabilities.

⁶⁸³ Green, *supra* note 461 at 151.

⁶⁸⁴ *Ibid.* Also Green, Darling & Wilbers, *supra* note 397.

burdened by “daily hassles of caregiving” as opposed to emotional distress.⁶⁸⁵ The latter falls under the category of subjective burden in Green’s own typology.⁶⁸⁶

Sabzevari et al studied burden of care in mothers with children with congenital heart disease in Iran.⁶⁸⁷ They describe children with serious health conditions, with medical complications, such as frequent hospitalizations, infections, dental problems and surgeries, similar to children elsewhere requiring complex forms of care. Their research found that mothers carry “catastrophic” burdens of care, and largely do so alone. Mothers *devoted* themselves to care, but relayed the *difficult realities* of such care.⁶⁸⁸

Green, Darling & Wilber’s research is a major contribution to the examination of such burdens of care for mothers. Burdens of care are complex, and may vary from one mother to another, depending on a variety of factors, and many burdens of care have both subjective and objective features. Building on their insights, I suggest that there is a range of political, legal, and social burdens of care. These impact mothers and disabled children differently, depending on a combination of different variables, like class and marital status. An example of a political burden of care is loss experienced through policy leading to state custody of one’s disabled child. As a burden, loss has profound objective and subjective aspects.⁶⁸⁹ Saetersdal, an academic and mother of a severely disabled child, complains that the discourse of normalization disallows the expression of suffering regarding having a disabled child.⁶⁹⁰ Her criticism might equally be levelled at critical disability discourses, which insist that expressions of maternal suffering *per se* are a reflection of ableism.⁶⁹¹

⁶⁸⁵ *Ibid*, at 128.

⁶⁸⁶ Green, *supra* note 461 at 154. Subjective burdens include feelings of guilt, resentment and entrapment associated with the child’s disability. It is the latter “subjective” features of care that critical disability theorists have honed in on, and subjected to critique.

⁶⁸⁷ Sakinne Sabzevari, Monisadat Nematollahi, Tayebah irzael and Ali Ravari. (2016) 4:4 “The Burden of Care: Mothers’ Experiences of Children with Congenital Heart Disease” *International Journal Community Based Midwifery* 374

⁶⁸⁸ Savzevari *Ibid* note 687 at 378

⁶⁸⁹ See Saetersdal, *supra* note 258; and Bruce, *supra* note 525. She writes about grief and trauma and also about “the inordinate and unrealistic demands placed on parents” in this conversation.

⁶⁹⁰ Saetersdal is Scandinavian. Normalization as an approach began in Scandinavia, reportedly through parent’s movements. It was written about by Nirje, a member of the Swedish Association for Retarded Children. It refers to a group of ideas directed towards having people with intellectual disability live lives that were as close as possible to the “normal” population. See Bengt Nirje, “The Normalization Principle and Its Human Management Implications” (1969, reprinted 1994) 1:2 *SRV-VRS Intl Social Role Valorization J* 19. Normalization included state support for intellectually disabled persons, such as pensions for seniors, child allowances, minimum wages and personal pensions, with the goal of having disabled people live at the same economic standard as others. It advocated against the sexual segregation of people with intellectual disabilities.

⁶⁹¹ In the past research from the medical model declared a disabled child to be a tragedy, and parents were described as chronically sorrowful. See S. Olshansky, “Chronic Sorrow: A Response to Having a Mentally Defective Child” (1962) 43 *Social Case Work* 190; Priyana Lalvani, “Historical Perspectives on Studying Families of Children with Disabilities: A Case for Critical Research” (2013) 33 *Disability Studies Q* 3. It was observed early on that mothers and fathers were not equally impacted in terms of their mental health, when a child was disabled. See S.E. Romans-

A little- addressed burden of care is the context where a child is violent. Stacey Clifford Simpican describes mothers' experiences with violent children as silenced in the field of disability caregiving. Quoting another mother, Anne Bauer, Simpican states, "[w]e cannot solve this problem [of violence] by hiding it, the way handicapped children themselves used to be tucked away in cellars."⁶⁹² Bauer's comment underscores the point that the circumstances of mothers with disabled children may be medically complex, physically challenging, dangerous, and emotionally difficult. It also points to the presence of forms of care that are "conflictual".⁶⁹³ Simpican states that a feminist disability theory should respond to violence endured by caregiving mothers, while also resisting ableist norms.⁶⁹⁴ What has not been addressed, that I will get to, is that these circumstances (burdens), to the extent that they are borne by primarily mothers, are legally problematic.

Should a mother seek state support, there is also a burden of regulation, and this may lead to the burden of legal disputes in both public and private law. Being surveilled and needing to engage in a dispute respecting support is both subjectively and objectively burdensome. Yet another burden is that of invisibility, as mothers are often invisible in discussions about childhood disability.⁶⁹⁵

Clarkson et al, "Impact of a Handicapped Child on Mental Health of Parents" (1986) 293:6559 *British Medical J* 1395. As discussed in my literature review, this is still the finding. Critical disability theorists pointed out that being the parent of a child with a disability was joyful and fulfilling and refuted findings of grief. Claire, the mother of a severely disabled child, in her Blog asserts that chronic sorrow can coexist with pride. See "Chronic Sorrow", (19 August 2011), *Life with a Severely Disabled Child: The Title Explains It All, Doesn't It?* (blog), online: <<http://severedisabilitykid.blogspot.ca/2011/08/at-loss.html>>. The assertion that perceived ongoing sadness is only as a result of ableism does not hold water, and Elizabeth Bruce refers to this terrain as being "an historical impoverished topic". Bruce, *supra* note 525 at 1. The denial of felt emotion is part of the burden of silencing (as Saetersdal states). Bruce writes also about disabled children's own grief, another area in need of more research.⁶⁹² Simpican, *supra* note 316 at 218 referring to Ann Bauer, "The Monster Inside My Son" (26 March 2009) Online: Salon <http://www.salon.com/2009/03/26/bauer_autism/>. Bauer was also an academic who published in the area of autism. See also Joanna Connor, "Kent State Professor Trudy Steuernagel's Fierce protection of her Autistic son, Sky Walker, Costs her Life: Sheltering Sky" (6 December 2009) online: Blog.Cleveland.com <http://blog.cleveland.com/metro/2009/12/kent_state_professor_trudy_ste.html>. Simpican writes that Trudy Steuernagel was beaten by her son, and put her into a coma from which she died. She left a note asking that her son not be punished should he kill her. Simpican, *supra* note 316 at 219, points out the difficulty in addressing invisible domestic violence, and doing so without adding to the stigma of the autism label. It should be noted also that this mother stated that she was isolated and that her husband had left. She was therefore a single mother with a severely disabled child in her full-time care. It goes without saying that she needed support, even though she was also relatively privileged in terms of qualifications, income and education.

⁶⁹² *Ibid* at 224-225.

⁶⁹³ *Ibid* at 230.

⁶⁹⁴ The wife of an applicant in *Tanudjaja v Canada (AG)*, 2014 ONCA 852, 123 OR (3d) 161 [*Tanudjaja*], was invisible. In *Tanudjaja*, claimants argued that in their dismantling of supports, along with failures to take steps to address housing needs in Canada, governments violated the *Charter* rights of those homeless or at risk of homelessness. The unnamed wife occupies a social location that is emblematic of care that may be encountered by otherwise marginalized *married* women in the setting of disability. Mrs. Mahmood, the intersections she found herself at were those of immigrant status, sex, gender, poverty, disability and disability status *by proxy*, caregiving intimate partner and dual maternal statuses. *Burdens of care are not uniform*, and those of Mrs. Mahmood were oppressive, even though she was married.

The study of burdens of care is immensely useful because it shows us where mothers and disabled children require support. Green's approach is relevant to any discussion of legal rights to support for mothers with severely disabled children.⁶⁹⁶ Importantly, Green, Darling & Wilbers comment on paradoxes that exist in mothering disabled children, where heavy care burdens may coexist with positive features of relationships with disabled children.⁶⁹⁷ Neither the charity nor the social model is capable of accommodating these paradoxes. The combined approach, as a model of care, accounts for the realities of severe impairments *and* maternal love and appreciation of one's child, making clear that the presence of one in no way precludes recognition of the other. Those researching in this area must be able to hold these features simultaneously, without fear of conflating the need for *vastly higher* levels of state support with rejection of the disabled child or a failed mother. These conflation are oppressive and wrongheaded. In their articulation, they have been violent.

Green and Green *et al's* approaches do not focus on what benefits disabled children confer on caregiving mothers, rather they ask how the relationship of severely disabled children and their mothers can best be supported. The combined approach to disability care is the only one that moves beyond the charitized approach, where mothers provide complex, often medically-oriented care, at great personal cost. In order to illustrate the point of a charitized mother and private care burden, I now discuss a Supreme Court of Canada disability rights case wherein the court's vision of disability support completely lost sight of the caregiving mother's rights and personhood and an aspect of the disabled girl's humanity.

Going Judicial – The Legal Turn Among Caregiving Mothers⁶⁹⁸

E. (Mrs.) v Eve is a well-known disability rights case that illustrates law's coercive arm ensuring mothers assume care, even when it is inappropriate for them to do so, and even where a mother initiated the action to avoid having to assume care for an additional generation. *Eve*⁶⁹⁹ thus exposes problems with responsibilization that mothers⁷⁰⁰ with disabled children share when they come before courts in matters

⁶⁹⁶ It is important to note that medical research more recently includes a focus on benefits. See Carnevale et al, "Daily Living", *supra* note 360.

⁶⁹⁷ *Ibid.* I am discussing two papers one by Green, *supra* note 461 and one by Green, Darling & Wilbers, *supra* note 397.

⁶⁹⁸ "Going judicial" are the words of Anne Larcade, quoted in Kathryn M. Olson, "Rhetorical Leadership in Framing a Supportive Social Climate for Educational Reforms Assisting Children with Disabilities" (Paper presented at the Oxford Round Table, Oxford, England, 28 March 2006) [unpublished, online: The Alexander Foundation <<http://www.thealexandrefoundation.com/press/oxfordpaper.pdf>>] at 3.

⁶⁹⁹ This case originated in PEI in 1981.

⁷⁰⁰ See also *Re Eve* (1980), 115 DLR (3d) 283 at para 4, 27 Nfld & PEIR 97 [*Re Eve* (1980) cited to DLR], the judge opined that "Mrs. 'E.' motivation was by no means entirely self-centered." This statement is telling. Not wanting to provide full time care and to financially support to a child not one's own as a widow may be construed as being self-centered.

concerning their disabled children. The facts of this case are as follows. The late Mrs. E. objected to the possibility of becoming a custodial grandmother during the last years of her life, in spite of the benefits she had enjoyed caring for her adult daughter Eve, who had an intellectual disability and who was not decisionally capable.⁷⁰¹ Once when Eve had expressed interest in a young man, the then almost 60-year-old Mrs. E became concerned about Eve becoming pregnant, becoming a mother and of she (Mrs. E.), having to raise Eve's child. As a result of these concerns, Mrs. E. asked a doctor to perform a tubal ligation on Eve. A referral was made by the family doctor to a surgeon, with the surgeon stating he could not perform the procedure without a court order giving him the authority to do so. Mrs. E subsequently sought an order to declare Eve incompetent pursuant to the *Mental Health Act*, so that she, Mrs. E. could be the decision maker respecting Eve and be permitted to consent on Eve's behalf.⁷⁰² The judge rejected Mrs. E's request to become a substitute decision maker for Eve, and Mrs. E appealed to the Prince Edward Island Court of Appeal.⁷⁰³ There, the ruling in the Family Division was overturned. The appellate judges concluded that enough evidence had been adduced to allow the court, exercising its *parens patriae* jurisdiction, to consent to the procedure on behalf on Eve. The court determined it to be in Eve's best interests to be sterilized.

On appeal, the Supreme Court of Canada did not agree.⁷⁰⁴ The Court, opining that a surgical procedure without consent constituted battery, held that sterilization ought not to be authorized for non-therapeutic purposes under the court's *parens patriae* jurisdiction, as it was not in Eve's best interests. The court found that the fact that others may suffer inconvenience or hardship should Eve have a child cannot be considered in such a determination.⁷⁰⁵

This finding sits at the heart of the conundrum of *Eve*. The Supreme Court of Canada grappled with the best interests test, stating that its duty to protect the vulnerable must not become a duty to choose between two rights at the behest of a third party.⁷⁰⁶ The court seemed not to appreciate the degree to which Mrs. E was also vulnerable as an older single widow unable to provide further care and being denied the choice to protect herself against that possibility. It is unclear whether Mrs. E truly was a "third party" in the sense that word is ordinarily used in law. If Eve had a child, child welfare authorities would be looking to Mrs. E to put forward a plan of care. In such a case, Mrs. E would be a legal party to such an arrangement.

⁷⁰¹ I use the words benefits in this chapter, although I do not agree with the term. The better term would be relationship.

⁷⁰² *Re Eve* (1980), *supra* note 700.

⁷⁰³ *Re Eve* (1981), 28 Nfld & PEIR 359, 79 APR 359 [*Re Eve* (1981) cited to Nfld & PEIR].

⁷⁰⁴ *E. (Mrs.) v Eve*, [1986] 2 SCR 388, 31 DLR (4th) 1 at para 81 "in the present case, there is no evidence to indicate that failure to perform the operation would have any detrimental effect on Eve's physical or mental health."

⁷⁰⁵ *Ibid* at para 92.

⁷⁰⁶ *Ibid* at para 99. The right to procreate and the right not to. Rights around care which follow on procreation are not explored fully.

Although expressing sympathy for Mrs. E.'s position (something previously expressed in the lower court) that the operation being performed would reduce her "anxiety that Eve might become pregnant, and give birth to a child, the responsibility for whom would probably fall on Mrs. E.", the Court opined that the procedure was for non-therapeutic reasons.⁷⁰⁷ It is interesting that the Supreme Court chose to use the word "anxiety" when setting out the potential grandmother's largely excluded position. Anxiety is an emotional state of unease, and the courts' stated sympathy for her was an expression of an emotional position (sympathy). Caregiving mothers' burdens of care are not only emotional (or subjective), as social model advocates suggest in dismissing their concerns as reflective of ableism. Mrs. E. may or may not have had anxiety, but her legal position was founded in rational concerns about the threat of further care obligations, which for her, would comprise coercive care. She was also concerned about her newly sexually aware daughter in a very ordinary way.⁷⁰⁸

There were three intervenors in *Eve*, one was the Consumer Advisory Committee of the Canadian Association for the Mentally Retarded.⁷⁰⁹ The stated goal of the Advisory Committee in advancing Eve's legal rights was to protect Eve from "the biased interests of care-givers."⁷¹⁰ As noted previously, this language respecting a caregiving mother reflects the transplantation to caregiving mothers of critiques from disability rights respecting public caregiver failures to act in the interests of those with disabilities. Ultimately, Mrs. E. found herself in the position of litigating against her own daughter, having realized that society was content to have her bear the risk of (harm) having to care for Eve *as well as* any child Eve might have until her (Mrs. E.'s) death (unless she was prepared to allow child welfare to take Eve's child into state care).⁷¹¹ She was not free to plan for retirement. Mrs. E. did not want the responsibility of a baby and she cannot be faulted for that, although apparently she was.⁷¹²

The disability rights community chose not to address the risks of adoption or institutionalization of Eve's potential child. Olesen observes that law is not responsive to the needs of 'families' (mothers,

⁷⁰⁷ *Re Eve*, *supra* note 700 at para 81.

⁷⁰⁸ There is an irony here as the disability communities' attribution of intent to *Eve* in respect of Eve's right to reproduce may itself be described as ableist. Eve appeared to be interested only in having sex, like many non-disabled youth. Mrs. E. was not prudish or uncomfortable with this, but others may have been.

⁷⁰⁹ See Vanhala, *supra* note 676 at 993. In 1985 'CAMR' became the Canadian Association for Community Living (CACL). The CAMR acquired intervenor status through the Consumer Advisory Committee in *Eve*, *supra* note 676 at 994. See *E (Mrs.) v Eve* (1986).

⁷¹⁰ Amy Spady, "The Sexual Freedom of Eve: A Recommendation for Contraceptive Sterilization Legislation in the Canadian Post *Re Eve* Context" (2008) 24 Windsor Rev Legal Soc Issues 33 at 50, referencing Sheila Wildeman, "The Supreme Court of Canada at the Limits of Decisional Capacity" in Jocelyn Downie & Elaine Gibson eds, *Health Law at the Supreme Court* (Toronto: Irwin Press, 2007).

⁷¹¹ Though history places Eve's mother on the other side of maternal disability rights activism, as someone holding back the advancement of rights for disabled persons. See Panitch, *Accidental Activists* (Dissertation), *supra* note 177.

⁷¹² Moreover, adoption agencies and child welfare agencies did not and do not place infants or small children with single women close to retirement age. Yet this possibility existed for Eve's mother.

primarily) with whom intellectually disabled persons most often reside.⁷¹³ In denying Mrs. E's application to allow her to consent on Eve's behalf, the trial judge failed to support Mrs. E.'s autonomy by responsabilizing her for the care of another adult's child, even as an unwilling senior.

The court also, one assumes, inadvertently failed to support one of Eve's other interests, that of her mother's economic and physical well-being, especially considering the level of Eve's dependency on her mother and her mother's advancing age.⁷¹⁴ Eve's interests as framed by disability advocates jeopardized Eve's significant interest in having her mother stay well and capable of playing a role in her life. A full contextual analysis is missing in the Supreme Court of Canada decision and my comments are designed to fill this omission.

The appellate court, which had overturned Justice McQuaid's family division decision, gave weight to the mother's affidavit evidence that it would be in both her *and* her daughter's interests for Eve to have the procedure. There, relational interests prevailed. That court stated succinctly, "She is a widow, approaching sixty years of age, and would inevitably be left with the care of any child which might be born. She feels that, at her age, this would be a responsibility with which she would have great difficulty coping, and quite understandably so."⁷¹⁵

Interestingly, the *Eve* case has been seen and taught as a "win" for disability rights.⁷¹⁶ The right of 60 year-old Mrs. E. not to be put in *loco parentis*, at a time when she would be an older adult *still*

⁷¹³ Colleen M. Olesen, "Eve and The Forbidden Fruit: Reflections on A Feminist Methodology" (1994) 3 Dal J Leg Stud 231, references Elizabeth Scott, "Sterilization and Mentally Retarded Persons: Reproductive Rights and Family Privacy" (1986) 1986:3 Duke LJ 806 at 808.

⁷¹⁴ Eve's best interests are the only ones the court deemed relevant by the Supreme Court of Canada.

⁷¹⁵ *Re Eve* (1980), *supra* note 700 at para 43. I note that the judge did not criticize Mrs. E for not being able to "cope" with the care at age 60 or older of Eve *and* any children Eve might have.

⁷¹⁶ Leilani Muir has spoken publicly about the horrors of sterilization. The experiences of intellectually disabled women who were sterilized have been discussed widely in the literature. See for example, Marcia Rioux & Lora Patton, "Beyond Legal Smoke Screens: Applying a Human Rights Analysis to Sterilization Jurisprudence" in Marcia Rioux, Lee Ann Basser, Melinda Jones eds, *Critical Perspectives on Human Rights and Disability Law* (Boston, Martinus Nijhoff, 2011) 243. Their chapter is situated in a section of the book entitled "Ensuring Equality", which points out that disabled women have historically lacked equality rights, including those relating to their reproductive role. However, in *Eve*, in considering the right to equality, we are also called upon to consider what would likely have happened if Mrs. E. was unwilling or unable to help Eve, as was the case. Eve's child would have been made a ward of the state pending adoption. and possibly institutionalized in a care-home or in foster care. This reality was not addressed by the court or by the intervenors, nor by disability rights activists, who ought to have concerned themselves with the real-life context of life for Eve's infant and Mrs. E. As others have pointed out, *Eve* was about the vindication of past human rights violations and not so much about Eve or her potential offspring. See P. Simons, "Fertility Rights: Mentally Disabled Adults Are Legally Protected Against Threats of Sterilization but the Freedom to Have Babies Raises Another Issue: Who Should Raise these Children? Sterilization: Alberta's Uneasy History", *Edmonton Journal* (11 February 1996) E1. Rioux and Patton in "Beyond Legal Smoke Screens" comment that courts were being asked to consider issues such as the difficulties of menstruation and the capability of intellectually disabled women to care for an infant, as comprising reasons to sterilize them, and the case of *Eve* is one of those discussed by them. They also comment that parents were arguing that it was in the child's best interests to be sterilized, and Rioux and Patton refer to this as "paternalistic notions of protection of a person with an intellectual disability" and as essentially veiled eugenics. I do not agree that the *Eve* case was about eugenics. *Eve* was more about the right to enforce caregiving maternity on a grandmother who had already been a caregiving

caregiving for her daughter on weekends and holidays as it was, was simply not recognized by the court. Some years after the decision however, former Supreme Court of Canada Justice, Bertha Wilson, stated in a paper on the constitutional protection of privacy in regards to the finding in *Eve* that, “the finding that the interests of care-givers are to be disregarded obviously has problematic consequences for women. Since it is primarily women who carry the burden in our society of child rearing, it would likely be a woman and not a man who would be responsible for rearing the child of a woman like Eve.”⁷¹⁷

Eve’s mother’s rights ought to include the right not be forced unwillingly into lifetime maternal caregiving to another person’s child (regardless of her relationship to that child). The absence of a legal term for the expectation that a woman must do so can be easily remedied. It is a form of involuntary domestic servitude. The servitude aspect of it is hidden within the word “mother”, where it has no place. In keeping with the former Justice Wilson’s viewpoint expressed in this same paper, we must adapt doctrine to accord with contemporary reality.

Vanhala states that *Eve* was part of a larger shift towards a disability rights model,⁷¹⁸ a model that evidently does not serve single mothers.⁷¹⁹ Mrs. E. had become conscious of the legal complexity in her and her daughters’ *joint* circumstances. She was strong enough to see her claim through and to endure vilification. *Eve* teaches us that, in law, mothers with disabled children forgo full legal personhood, even

mother. It concerned therefore a senior who had cared for a much-loved disabled daughter and who was alert to the fact that she could not care for another child. Whether she ‘could’ do so was one issue. The other salient issue was that *she did not want to*. The section in which Rioux and Patton’s essay appears called “Ensuring Equality” omits an analysis that equality and the autonomy it promises, *is for all*, including women with adult disabled children. The case of *Eve* provides an example of the disappearing of women’s rights in some disability advocacy and it is sexist in its basic assumptions about the legal rights of Mrs. E. *Eve* challenges us to consider that the realization of disability rights involves more theorization where women and children and care are concerned.

⁷¹⁷ Bertha Wilson, “Women, The Family, and the Constitutional Protection of Privacy” (1992) 17 Queen’s LJ 5 at 18.

⁷¹⁸ In her book, *Accidental Activists: Mothers, Organization and Disability*, *supra* note 153 at 137, Panitch quotes Audrey Cole, an activist mother and key player in CAMR and the Consumer Advisory Committee, as stating that she was firm in her commitment to promoting certain values when eager to advance the rights of Eve. Disability rights have not been advanced along one axis alone and this both complicates and troubles the situation of children with severe disabilities and their caregiving mothers. Cole had a retired pensioned husband at home to care for her son, leaving her free to advocate politically, and was in a privileged position in this regard. She also did not have a disabled daughter who might become pregnant and present her with another child to raise. She did not have to face the economic or health risks Mrs. E. faced as a potentially “until-death” sole care-giving mother. Also worthy of note, is that according to information provided in a 2007 interview with the then Executive Vice-President of CACL, it was “sharply divided” in deciding whether or not to intervene in the *Eve* case, where to do so was to go against the legal claim of a parent. Vanhala, *supra* note 676 at 994.

⁷¹⁹ The evidence of Dr. Saunders at the trial was reviewed in *Re Eve* (1980), *supra* note 700 at para 13. He provided evidence as a physician that a tubal ligation would be the least of all complications for Eve. He stated that as the father of an intellectually disabled son, had his son been a daughter, he would have “been to court” with the same issue Mrs. E. brought to court. His testimony highlights differential impact of (a) being a single mother with a disabled child and (b) having a disabled child who is female. Thus again gender comes to the fore in the arena of disability rights. Eve sought to be sexual, not reproductive, and that did not sit well in that community at that time. She lost her first and only boyfriend due to prudish community fears. According to reliable information passed along to me, the Executive Director of the Prince Edward Island Association for Community Living confirmed that Eve did not go on to partner with anyone. Mrs. E has passed away.

as others are publicly asserting their related rights. In this context, problems with maternal personhood occur not only in civil litigation about decisional capacity, but also in family and child welfare law, as well as in social benefits litigation.⁷²⁰ Nisrine Mansour states that “at the judicial level women’s legal personhood is blurred in both legal texts and judicial practice”, and the *Eve* decision supports her insight.⁷²¹ This is because the disability rights model, like that of law in general, struggles with justice concerns where there are mothers and children with what are fundamentally *relational* rights. The relational nature of these rights was captured in a narrative published in 1994 by an Alberta mother, Donna Haslam, in an account of how her burdens of care were impacting on her. In “Public Policy that is hazardous to women’s health: Privatization and long term care,” she was not extolling the joys of mothering, features that are *private* and to which she alludes. Rather, she wrote to expose the oppression that she experienced. I argue that she did so to break the culture of silence, which Freire states cements social myths.

Haslam wrote about the difficulty in finding residential care while providing care at home. She described her decision to find state care during the late 1960s as being “painful.” She described long wait lists and a lawyer’s letter to Alberta Premier Peter Lougheed to access a placement. She describes herself as someone “teetering on the edge of emotional exhaustion.” The latter was due to the lack of services for her daughter’s care.

Haslam, whose ponderings suggest transformed awareness of her circumstances, stated, “I’ve also been haunted by the phantoms of motherhood and of community living. It’s time to let go of these illusions. Giving birth does not chain me to lifelong responsibility for my beautiful daughter and there is no existing community that can provide the care that Karen requires.”⁷²² Her statement likewise suggests new found critical conscious insight which she felt compelled to share publicly. She added that women are pushed to the limits of endurance and cannot “be expected to carry excessive burdens of responsibility in caring for loved ones in our homes. We need to move toward social care and shared responsibility. Neither can we be expected to place them in large crowded institutions nor in private homes and agencies with public funds.”⁷²³

Haslam’s narrative speaks of love *and* excessive responsibility. She refers to the experience of social abuse, which corresponds to the social violence against mothers and their severely disabled

⁷²⁰ I refer to the problem of applying the liberal notion autonomy vis-à-vis caregiving mothers accessing support through Ontario disability support law for severely disabled children in Chapter Six.

⁷²¹ Nisrine Mansour, *Governing the Personal: Family Law and Women’s Subjectivity and Agency in Post-Conflict Lebanon* (PhD Thesis, London School of Economics and Political Science, 2014) [unpublished, archived by LSE Theses, online: <http://etheses.lse.ac.uk/3183/1/Mansour_governing_the_personal.pdf>]. (I emailed her for full paper July 3, 2015).

⁷²² Donna D. Haslam, “Public Policy that Is Hazardous to Women’s Health: Privatization and Longterm Care” (1994) 14:3 *Can Woman Studies* 114 at 116.

⁷²³ *Ibid.*

children. I include her story because it was written over twenty years ago, yet situations remain dire for many caregiving mothers whose children require a range of such supports. Haslam moves on to address shared responsibility for providing care to severely disabled children, something a mixed model of childhood disability supports. That responsibility must be found in law. Yet, when one looks to the current law, one sees it is ill-suited to the task of supporting caregiving mothers with severely disabled children.

My various discussions in this chapter concerning the characterization of care by the state and others and the different ideological orientations towards it are central to my dissertation. They illustrate the many ways in which mothers of all ages have been heavily responsabilized for many forms of disability care from different quarters, with no regard paid to the impacts of that on their and their disabled children's social or economic survival. However as seen in the scholarly writing of Green and Haslam as well as the legal case brought by Mrs. E, caregiving mothers over a lengthy period have not accepted the political and legal status quo, which assigns mothers risky forms of long-term care.

In Chapters Six and Seven, I illustrate how mothers have tried, in their use of law, to shake off their having been thus responsabilized. Before I do that, I set out the law and policy landscape they must struggle with in Chapter Five.

CHAPTER FIVE: The Legal Landscape

Introduction

Support law does not exist in a vacuum, but rather in historical, political, and cultural contexts. Dominant representations of care discussed in the previous chapter are translated into law through mechanisms of governance.⁷²⁴ How dominant representations are translated into law is complex, much analysis of which is beyond the scope of my project. Here, I aim simply to provide a backdrop to Canadian policy and its adjudication sufficient to give context to legal analyses that follow.

Given the complex features of the disability policy involved, it is apt that presenting policy in a coherent manner proves to be a challenge. It is not only that Canadian childhood disability policy is complex; it is also difficult to access and not easy to understand. In addition, there are perplexing features to such policy with no means to address them. Thus, disability support policy is shrouded in mystery. In order to present a picture of the kind of supports on offer, first, I describe the federal/provincial division of powers and constitutional jurisdiction as it pertains to disability, and move on from there to critique approaches to it. Subsequently, I describe the system that deals with legal issues that arise in these areas. After this, I discuss two benefits the state provides: homecare and respite. I present Ontario as a case study, filtered through the lens of my own standpoint. I end this chapter with a description of private support. This is important because private supports interact with public supports and because law and cases in this area are informative on the matter of support overall.

First though, a comment on where childhood disability policy rests in terms of ‘importance’ in the overall policy landscape. My review described how disability policy concerning disabled children lacks national focus or, indeed, interest.⁷²⁵ It also showed that policy has kept pace neither with developments in medicine nor in society. Yet child medical disability policy is on national radars elsewhere. In the US in 2000, funding was made available for a National Survey of Children with Special Health Care Needs in order to evaluate the prevalence and effects of conditions on children and their families.⁷²⁶ The goal was to improve their circumstances.⁷²⁷ In the same timeframe, the Ontario government stopped entering into special need agreements (SNAs) for severely disabled children. Neither Ontario government

⁷²⁴ Some examples of visual state representations of care are illustrated at Appendix C, where care is shown to be performed by high status beautiful young women involved in well known disability related charities. The message is that it is feminine and noble to provide care to disabled children.

⁷²⁵ See Prince, “Hit and Miss”, *supra* note 442 at 76.

⁷²⁶ See Peter C. van Dyck et al, “The National Survey of Children with Special Health Care Needs” (2002) 2:1 *Ambulatory Pediatrics* 29 at 29.

⁷²⁷ *Ibid* at 34, 37. In particular, whether families were getting the information they required.

research nor the legislature supported this,⁷²⁸ suggesting that Ontario is not in step with this area of health policy for example, seen in the USA.

Van Dyck et al. comment that the US Federal and State maternal and child health provisioning has a century long history of together governing “a foundation and structure to ensure maternal child health.”⁷²⁹ In 2006, there was another National Survey of Children with Special Health Care Needs conducted in the US. In Canada, on the other hand, federal efforts were in the opposite direction, aimed at terminating the federal disability survey, which provided information to government about disabled children.⁷³⁰

Children who are severely disabled are not a Canadian phenomenon, and their support needs are internationally understood. Indeed, in 2003, the Institute of Medicine in the United States named children with special health care needs as a priority area in health policy.⁷³¹ It is unclear to what extent our provincial policymakers are aware of what is taking place elsewhere, but our policy regime is outdated, a feature with implications in international human rights law. The literature review described support needs in the setting of medical disabilities that would be similar across jurisdictions.⁷³² Canada has not kept up with need, which, in turn, means that needs are difficult to meet. Another problem is that the provinces and territories determine the delivery of these programs individually. Our constitutional division of powers may be considered one of the factors that hampers the realization of support rights to caregiving mothers.

Provincial Jurisdiction over Disabled Children and Caregiving Mothers

Section 92 of *The Constitution Act* grants the provinces powers over property and civil rights.⁷³³ While matters such as child welfare, social assistance and healthcare fall within these heads of provincial jurisdiction, the federal government nonetheless plays a significant role through the transfer of funds to the provinces.⁷³⁴ Mothers with disabled children look to these domains for state support. Provinces have relative autonomy to make decisions about how these areas are dealt with. There is a broad structural

⁷²⁸ See e.g. Contact Hamilton, *Community Plan*, *supra* note 459. Other research, such as that of Chiodo et al, *supra* note 459, partially funded by an anonymous donor through the United Way, and the City of London and the County of Middlesex. A major finding in this document was care delivery was a source of “major family stress.” *Ibid* at 2.

⁷²⁹ van Dyck et al, *supra* note 726 at 29.

⁷³⁰ See Statistics Canada, “PALS: Report”, *supra* note 106.

⁷³¹ See Cohen et al, *supra* note 32 57. He is a Canadian medical scholar writing about the US situation.

⁷³² See for example the Australian article by Wang & Barnard, *supra* note 383.

⁷³³ *The Constitution Act* *supra* note 10.

⁷³⁴ This is the case even though the arrangement under the Canada Assistance Plan was roled into other transfer arrangements in 1995, namely the CHST and the CST. See “History of Health and Social Transfers” online: Department of Finance Canada <<http://www.fin.gc.ca/fedprov/his-eng.asp>>.

similarity in the bureaucratic system of governance of such policy across Canada.⁷³⁵ Offerings across the country, too, are broadly similar. For example, all provinces provide funding for respite care to parents.⁷³⁶ The background to the federal cost-sharing in the funding of such programs for the provision of assistance and welfare began with the Canada Assistance Plan (CAP). CAP was in place from 1966-1965. Through CAP the federal government shared eligible costs 50-50 with the provinces for social services, although it later introduced a “cap on CAP” for the provinces of Ontario, Alberta and British Columbia. In 1995 the Liberal federal government cancelled CAP and implemented the Canada Health and Social Transfer (CHST). This was block-funding transfer that combined CAP with several other transfers. Unlike CAP, which attached significant conditions to the federal payments and earmarked funding for social assistance, the CHST was an unconditional block grant to cover health care, post secondary education, social assistance and social services and provinces were free to decide how to apportion funds as between these broad policy domains.⁷³⁷ However it did retain conditions as to what provincial public health plans had to be like as seen in ss 7 -12 of the *Canada Health Act*. Federal funding to the provinces was again restructured with the introduction of the Canada social transfer and the Canada Health Transfer (CHT) with 62% of federal funds under CHST being allocated to the CHT, and only 38% for everything else. Since the mid 1990’s therefore the federal government has provided largely unconditional transfers of money to the provinces and territories towards post-secondary education, social assistance and social services.⁷³⁸ Thus, in any given province or territory, respite may be available to eligible children through different Ministries simultaneously, and with different regulations governing funding in each. This is

⁷³⁵ Quebec has a different apparatus for state supports. Quebec caregiving mothers do not have a better ability to realize their legal rights to support, however. The work of Franco Carnavale has exposed shortcomings in the system of supports for those with medically fragile and technology dependent children, see for example, Carnevale et al, “Daily Living”, *supra* note 360. There have also been newsreports revealing the struggles caregiving mothers have in accessing support. i.e. Solyom, *supra* note ##. This is not recent as evidenced by commentary in the aftermath of the Blais case, discussed elsewhere in this dissertation. Alberta has legislated some reforms in its law pertaining to support for children with disabilities. However, supports remain centered in the family and there are wait lists. A video clip of the Alberta Human Services government websites shows footage of white, middle class, mid-aged, well dressed couples sitting on couches or at tables with their disabled children in their homes, stating why they need services provided through that province’s *Samantha’s Law*. “An Introduction to Alberta’s Family Support for Children with Disabilities (FSCD) Program” (29 August 2011) (Youtube Clip) online: Alberta Human Services <<http://humanservices.alberta.ca/disability-services/14855.html>>. The bureaucrats who speak refer to services building the capacity *of families* to support the child *throughout life*.

⁷³⁶ Respite is provided through the Ministries of Health and Long Term Care in Ontario, Human Resources in Alberta, the Ministry of Children and Family Development in British Columbia, Community and Social Services in Nova Scotia and Ontario, or may be provided regionally through other health entities like Centres Locaux de Services Communautaires in Québec.

⁷³⁷ Ronald D. Kneebone and Katherine G. White. See “Fiscal retrenchment and Social Assistance in Canada” (2009) 35: 1 Canadian Public Policy/Analyse de Politiques, 21, 22-23.

⁷³⁷ Ronald D. Kneebone and Katherine G. White. See “Fiscal retrenchment and Social Assistance in Canada” (2009) 35: 1 Canadian Public Policy/Analyse de Politiques, 21, 22-23.

⁷³⁸ See discussion in Thersa Shanahan and Glen A. Jones. “Shifting Roles and Approaches: Government Coordination of Post-secondary Education In Canada, 1995-2006” (2007) 26:1 Higher Education Research and Development, 31 at 33.

reflective of the overlapping that occurs in disability policy for children. All provinces likewise provide disability income to disabled people, as well as supports to mothers (parents). Support is structured as a benefit for the disabled child, and for an adult disabled ‘child’ living at home.⁷³⁹ To qualify, there are income criteria, and stipulations as to how the money is to be spent. Provincial government policymakers determine what supports will be made available and define their scope.⁷⁴⁰ The Federal disability tax credit⁷⁴¹ is not an impactful disability benefit for all caregiving mothers, both because it is meager in relation to the costs of disability and because is unavailable to mothers living on social assistance. Its stated aim is greater tax equity.

Critique of Policy Approaches

If state supports to disabled children and their mothers were ever adequate (something that no one has shown), it was readily apparent by the mid-1990s that they had failed to keep pace with needs. In the context of medical advances, political changes (the political turn to the right and the changes in Federal funding arrangement to the provinces), and social change (the disability rights movement, many more women in the labour force), the issue of support for disabled children came to a head in cross-provincial litigation in a variety of ill-defined areas *vis-à-vis* childhood disability. Notably, *Auton (Guardian ad Litem) v British Columbia*⁷⁴² was brought under British Columbia’s *Class Proceedings Act*, with parents and their children challenging provincial refusal to fund an autism therapy.⁷⁴³ This litigation was commenced against a Ministry of Health and was terminated with a Ministry of Education as the opposing party. In Ontario, the issue became politicized and later litigated in Ann Larcade’s litigation concerning Special Needs Agreements (SNA) in roughly the same time frame.⁷⁴⁴ Primarily, caregiving

⁷³⁹ For example, the Saskatchewan Community Living Service Delivery, a branch of that province’s Ministry of Social Services, offers respite funding that is paid monthly to families with a child with intellectual disabilities. “Community Living - Respite Program” (Regina: Author, 2014) online: Saskatchewan Ministry of Social Services <<http://publications.gov.sk.ca/documents/17/30344-Family-Respite-Program-factsheet.pdf>>.

⁷⁴⁰ They do this in part through recommendations made in research conducted by organizations that compete with one another in proposal competitions to undertake the government-funded research.

⁷⁴¹ Which is further discussed below.

⁷⁴² *Auton (Guardian ad Litem) v British Columbia (Minister of Health)* (1999), 12 Admin LR (3d) 261, 87 ACWS (3d) 434, [*Auton* (1999) cited to Admin LR]. This case made its way up to the Supreme Court of Canada with claims the province was violating the *Charter* section 7 and 15 rights of the plaintiffs.

⁷⁴³ See Manfredi & Maioni, *supra* note 6 at 127. A group of parents, primarily mothers, sought certification, unsuccessfully. The *Auton* (2004), *supra* note 1139 case at the Supreme Court of Canada had 10 government intervenors. Manfredi and Maioni state this demonstrated the importance of the case.

⁷⁴⁴ In the case of Ontario, see K. Goldstein & J. Finlay, *Special Needs Agreements: Guardianship or Critical Services: Parents Dilemma* (Toronto: Office of Child and Family Service Advocacy, 2000). See *Larcade v Ontario (Minister of Community and Social Services)*, [2005] OJ no 3156 (ONCA).

mothers' advocacy made it apparent that as stakeholders, they held different understandings than did the state as to responsibility for such support.⁷⁴⁵

In 2002, in the midst of legal activity and advocacy, Canadian disability policy expert Michael Prince commented that until the 1980s, little attention was paid to Canadian disability policy. He noted then that it is "only in the last five years that the federal government in concert with provinces and territories has articulated a family policy under the National Children's Agenda, and one that initially made no direct reference to children and disabilities."⁷⁴⁶ In the government's favour, Prince pointed to the development of increased use of public policy consultations where families with disabled children are concerned.⁷⁴⁷ In spite of this, as discussed, little is known about the numbers of children with severe disabilities in Canada for whom policy still must be tailored. Nor is there adequate information as to how mothers meet their needs, even in realms where there has been consultation.⁷⁴⁸

The tendency is to house disability benefits within programs other than social assistance.⁷⁴⁹ However, where mothers and disabled children are concerned, social benefits are contained in 'programs' that have retained features of social assistance.⁷⁵⁰ As well, many caregiving mothers live on social assistance themselves.⁷⁵¹ This may help to explain why little is known about how caregiving mothers manage, since in such a begrudging environment little concern has been shown for how caregiving mothers cope. Scholars outside Canada have tackled policy problems in the area of social benefits to severely disabled children. Blum in the United States has done so, for example.⁷⁵² My review alluded to other research on this from the US, and that literature may be referred to for information as to what is problematic for poor caregiving mothers being "supported" by "welfare".⁷⁵³

In the Canadian context, in spite of noted structural similarities among provincial benefit governance, it is difficult to make generalizations about specific supports at any given time, as programs

⁷⁴⁵ In fact, there was a great deal of litigation in this time frame, as I discuss elsewhere.

⁷⁴⁶ Prince, "Governance", *supra* note 437 at 390.

⁷⁴⁷ *Ibid* at 393. However, anecdotally mixed experiences have been reported with such public consultations.

⁷⁴⁸ The mere fact of public consultation does not mean policy-makers adopt the perspectives advanced in such consultation. Moreover, mothers with chronically ill children are often too exhausted and too busy to participate in consultations, even if we are invited to do so. Among women who do so, how many are single mothers with children with multiple disabilities or who have multiple children with disabilities?

⁷⁴⁹ See *ibid* at 398.

⁷⁵⁰ For example, stringent eligibility criteria requiring collateral evidence reluctantly with an undercurrent of guarding against "welfare" fraud See Dorothy Chunn & Shelley Gavigan, "From Welfare Fraud to Welfare as Fraud: The Criminalization of Poverty" in Gillian Balfour & Elizabeth Comack eds, *Criminalizing Women: Gender and (In)Justice in Neoliberal Times* (Black Point, NS: Fernwood, 2006) 217.

⁷⁵¹ See Roeher, *Finding a Way in*, *supra* note 24 at 7.

⁷⁵² Blum frames one problem as mother's having to manage dense bureaucracies, medication and stigma, at once. Linda M. Blum, *Raising Generation RX: Mothering Kids with Invisible Disabilities in an Age of Inequality* (New York: New York University Press, 2015) at 35.

⁷⁵³ See e.g. Doolittle, *supra* note 446 and Litt *supra* note 446 at 78.

change frequently.⁷⁵⁴ The stated aim in all programs is that of assistance. The 1991 issue of the Ontario Special Services At Home (SSAH) policy guideline that I was provided as a caregiving mother states: “Government has a commitment to assist with the costs and required services by supporting a range of family support services.”⁷⁵⁵ Remaining stable however, are the strict eligibility requirements to be met by applicants to prove need. These raise doubts about the government’s commitment even to assist with costs, never mind to “share” in them more broadly as it claims to be doing.⁷⁵⁶

Another problem is inconsistency in programming inter- and intra- provincially. These are additional features that make it challenging to provide a coherent sketch of policy offerings.⁷⁵⁷ The extent to which jurisdictions compare their initiatives is unclear to government outsiders.⁷⁵⁸ However, the scope of services provided under a given program clearly varies between provinces. In order to access supports, there are different application processes and eligibility requirements.⁷⁵⁹ Support, moreover, is not presented neutrally in policy, and the way language is deployed is informative, particularly in the current legal contexts. For example, in Ontario, one website states that when applications are submitted for funding for disabled children, a “special agreements officer” will contact the applicant by letter.⁷⁶⁰ However, there are no longer special needs “agreements” made between the Minister or child welfare agencies and the parents of disabled children, and there have not been for well over fifteen years. Until very recently, this is a discretionary decision made by an “officer” and in fact, is not an agreement at all.⁷⁶¹ This hints at disingenuous features underlying some provincial policy.⁷⁶²

⁷⁵⁴ See Prince, “Hit and Miss”, *supra* note 442 at 71. Prince refers to “relentless, incremental change” which “conceals the erosion” of supports.

⁷⁵⁵ Ontario Ministry of Community and Social Services, *Guidelines for the Special Services at Home Program* (Toronto: Queen’s Printer of Ontario, 1991) (not paginated) [OMCSS, *Guidelines*].

⁷⁵⁶ The *ODSPA* states “[t]hat the purpose of this Act is to establish a program that ... (b) recognizes that government, communities, families and individuals share responsibility for providing such supports.” Assistance for Children with Severe Disabilities support is offered under this same program. Asserted in subsection (d) of the ODSP Program is accountability to taxpayers. There is no subsection respecting the states accountability to caregiving mothers. Lawyer Simon Shields states there is no case law on ACSD and one must look to the Director’s own pronouncements, which he states lack detail and as such are not useful. See Simon Shields, “Ontario Disability Support Program (ODSP) Law (01 November 2012) Chapter 5 - Assistance for Children with Severe Disabilities”, online: IsThatLegal.ca <http://www.isthatlegal.ca/index.php?name=severely_handicapped_children.odsp_law>.

⁷⁵⁷ See Senate, Standing Committee on Human Rights, *Children: The Silenced Citizens* (April 2007) (Chair: Raynell Andreychuk) [Senate Report, *The Silenced Citizens*].

⁷⁵⁸ My later discussion of Anne Larcade’s and Joyce Dassonville’s lawsuits against Ontario and Nova Scotia respectively, suggest a desire for consistency and cross-provincial coordination in approaches.

⁷⁵⁹ This involves eligibility driven definitions for a ‘disabled’ child, making it a challenge to discern who is under discussion in any given policy.

⁷⁶⁰ Ontario Ministry of Children and Youth Services, “Assistance for Children with Severe Disabilities” online: OMCYS <<http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/disabilities/index.aspx>> [OMCYS, “Assistance”].

⁷⁶¹ One must comply with the terms of eligibility, but that does not make it an agreement.

⁷⁶² In 2017 Bill 89 was introduced in Ontario and since then, after this research was conducted, 30 of the *Child and Family Services Act*, RSO 1990, c C.11 [CFS], which provided Special Needs Agreements has been repealed.

Another feature of policy is that Ministries may take on child disability support provisioning in areas not within their official mandate or funding frameworks. For example, provincial child welfare ministries may employ the legal fiction of “abandonment” from child protection legislation to provide placements to disabled children otherwise not provided provincially. Offerings may also change with each incoming administration, which may formulate new programs or change program criteria. They may even change the ministry in which programs are housed. Alternatively, policy may not formally change, but does so informally and without notice. In some cases, a new administration may come in and make sweeping changes without consultations, and this may result in long-term bureaucratic turmoil.⁷⁶³ Pinpointing what choices or information instigated the formation of new child disability policy may be a challenge. It is evident however, that one pathway to policy is a crisis. Provincial fatality and other inquiries have spurred review of policy towards support for severely disabled children.⁷⁶⁴ Litigation has also moved provinces to change their childhood disability support policy⁷⁶⁵ or court orders have required them to do so.⁷⁶⁶

There is overlap in support provisions intra-provincially. In Ontario, for example, the Ministry of Health and Long Term Care (MOHLTC) provides Home Care Services. A memorandum from the Deputy Minister of Education⁷⁶⁷ provides for the coordination of health-related services for children with disabilities through ministries of Health, Education, Community and Social Services, and Long-Term Care.⁷⁶⁸ Also in Ontario, supports may be sought through the Ministry of Community and Social Services

⁷⁶³ This is what took place in Ontario after changes were brought in in the mid to late 1990’s under the Conservative regime of Mike Harris. The fallout for children with severe disabilities wrought by this government as a result of the lack of planning remains a serious problem to this day.

⁷⁶⁴ See e.g. *Samantha’s Law*, which emanated from the circumstances of disabled Samantha Martin in Alberta, referred to *supra* note 290. The legal change was to no longer provide disability services through child welfare.

⁷⁶⁵ Including where the party bringing the action has not prevailed as in *Krangle (Guardian ad Litem) v Brisco*, 2002 SCC 9, [2002] 1 SCR 205 [*Krangle*].

⁷⁶⁶ See *C.R. v Alberta (Director of Child Welfare)* (1996), 190 AR 86, 43 Alta LR (3d) 179 (ABQB) [*C.R.*] The court in this case held Lovaas style treatment was a service for disabled children within the meaning of that province’s *Child Welfare Act*, SA 1984, c C-8.1. See Manfredi & Maioni, *supra* note 6 at 121.

⁷⁶⁷ Deputy Minister of Education, “Policy/Program Memorandum No. 81” (19 July 1984) online: Ontario Ministry of Education <<http://www.edu.gov.on.ca/extra/eng/ppm/81.html>>. What is interesting about this is the sharing between ministries for the provision of services in schools. “Policy/Program Memorandum No.81” states “support services will be shared among the Ministries of Education, Health, and Community and Social Services. Responsibility for the direct provision of these services at the local level will be shared by the school boards, the Home Care Program of the Ministry of Health, and agencies operating under the Ministry of Community and Social Services.” The Memorandum further states “The Home Care Program of the Ministry of Health, at the request of a school board, will be responsible for assessing pupil needs, and for providing such services as injection of medication, catheterization, manual expression of the bladder, stoma care, postural drainage, suctioning and tube feeding.” Teachers and their unions have a problem with teachers performing medical acts, and so trained nurses attend at school to provide nursing care. These are medical acts when performed by medical personnel, and non-medical professionals are not expected to perform them in the course of the performance of their non-medical duties, but mothers are. The care of children with complex care needs medicalizes mothers, but not teachers. The practice of medical care and the awareness that this is the reality is part of what changes mothers’ consciousness.

⁷⁶⁸ A child may require a nurse to perform medical procedures during school hours.

and through the Ministry of Children and Youth Services. The Assistance for Children with Severe Disabilities Program (ACSD) is mentioned on the website of the Ministry of Children and Youth Services, and is purportedly a program of the Ministry of Children and Youth Services.⁷⁶⁹ However, it is governed under the aegis of the Ontario Disability Support Program (ODSP) of the Ministry of Community and Social Services (MCSS).⁷⁷⁰ The same legislation that governs income support for adults with disabilities also governs disability support funding for severely disabled children.⁷⁷¹

Since policy formation falls within provincial/territorial jurisdiction, it is difficult to imagine how systems of supports can be strengthened nationally.⁷⁷² Although fiscally the federal government has enormous influence, it cannot be held accountable on its own, as it lacks jurisdiction to remedy non-federal problems. However, it has played a role in the existence of some problems. One of them already mentioned is insufficient national data about needs.⁷⁷³ One may conjecture as to why this is, although it has been stated that, “debates on understandings of disability and of childhood have persisted in compartmentalizing ‘children’ and ‘disabled people.’”⁷⁷⁴ This may be part of the explanation for the presence of the hodgepodge of child disability policies across Canada.

Prince’s remark that disability policy is generally uneven and fragmented,⁷⁷⁵ corresponds with what Goodley and Runswick-Cole have asserted in England, that “disabled children occupy a complex and contested policy domain in which their status as both ‘child’ and ‘disabled’ has to be negotiated and explained in the contexts of health, social care, education and leisure”.⁷⁷⁶ The comments of these experts give us insight into the challenging situation that caregiving mothers face when seeking support and perhaps also, the state’s challenges in providing them.

In Canadian support domains, mothers must provide ‘evidence’, advance positions and negotiate in attempting to get what they need. Given that child disability and maternal support policy emerge as

⁷⁶⁹ Information on social benefit programs subject to regulations under other Ministries is shown on the MCYS website.

⁷⁷⁰ A letter I received from an official with the Ministry of Community, Family and Children’s Services, Toronto Regional Office, dated 16 October 2002, notified me of the decision to award me \$5,500.00 in funding for that year. It showed SSAH and ACSD as both being on the same letterhead and under this same Ministry at that time.

⁷⁷¹ The Daily Bread Food Bank has published a brochure entitled “Overview of Benefits: Understanding OW, ODSP and other Government Benefits” (June 2015) online: Daily Bread Food Bank <<http://www.dailybread.ca/wp-content/uploads/2015/07/OverviewOfBenefits-June2015.pdf>>.

⁷⁷² Some policy scholars have suggested a national policy for children with disabilities and recently there has been suggested a federal equivalent to ADA.

⁷⁷³ One cannot point to negligence in federal oversight because it is not the role of the Federal government of Canada to oversee the sorts of policies that are under discussion here. However, they could provide much more detailed information with a focus on mother’s support needs nationally to provide to the provinces and territories.

⁷⁷⁴ Bronagh Byrne, “Minding the Gap? Children with Disabilities and the United Nations Convention of the Rights of Persons with Disabilities” in Michael Freeman ed, *Law and Childhood Studies: Current Legal Issues*, vol 14 (Oxford: Oxford University Press, 2012) 419 at 421.

⁷⁷⁵ Prince, “Governance”, *supra* note 437. See also discussions in Prince, “Hit and Miss”, *supra* note 442.

⁷⁷⁶ Goodley & Runswick-Cole, “Celebrating Cyborgs”, *supra* note 117 at 1.

complex and changeable networks of minimal supports, this is no easy task. Given that severely disabled children have a multitude of complex care requirements, clarification of governments' obligations to them is needed.

As stated, severely disabled children's needs fall across service mandates of different provincial ministries. Characterizing a particular "need" as either educational *or* health can create service difficulties for mothers whose children may need many forms of service simultaneously.

As a result of the ways in which 'care' is characterized in policy, other divides emerge. For example, complex care⁷⁷⁷ is characterized as either public or private care, as either healthcare or homecare, and/or as either formal care or informal care, respectively. Moreover, the care of children deemed by provincial policy to be *medically* complex is clearly also *maternally* complex, as I have described. The medically complex care label is typically attached to the child, a convention that disappears maternal complexity in policy altogether. To provide medically complex care also carries a different social status than does the provision of maternally complex care, so there are high status and low status types of care as an added duality.

This returns us to the issue of the importance of language in support policy provision. The naming of services in policies of care for disabled children (mothering, disability support, homecare, nursing, personal support or respite) have a bearing on whether that care is remunerated, at what rate it is remunerated, by whom and of course, where it is performed. Consequently, one sees that 'care' is a word subjected to multiple interpretations, in keeping with what Fraser and Gordon have discussed respecting the word 'dependency.' As Fraser and Gordon noted, the word 'care' also does 'ideological work'.⁷⁷⁸ The reality is that caregiving, like dependency, carries a stigmatized status. Jennifer Nedelsky goes so far as to state that "[t]he dominant culture of North America treats virtually all forms of physical caretaking with contempt."⁷⁷⁹ Being devalued, its value need not be appropriately recognized or recompensed. In fact, I would argue that care of disabled children, rather than being seen by the state and thus, in policy, as invaluable, is treated as though it has no value. This is reflected in legal cases I examine and is a feature that gets in the way of rights assertion. There is an inherent contradiction between the devaluing of care on the one hand and the placing of caregiving mothers on a pedestal, on the other. Although it may be perplexing to mothers early on and challenges them to be heard legally, caregiving mothers nevertheless call attention of the courts to their view of support arrangements in a manner that suggests critical awareness of the counterfactuals in the law and in how their claims are countered.

⁷⁷⁷ I prefer to use this term, as the care that is provided, while medically complex is complex across a range of factors but is primarily provided by mothers and it is primarily mothers who coordinate the other forms of care.

⁷⁷⁸ Fraser & Gordon, *supra* note 217 at 4.

⁷⁷⁹ Nedelsky, "Reflections on Mothering", *supra* note 304 at 34.

Returning to the issue of how policy operates, the practice of shuffling policies from one ministry to another makes it challenging at times to state what a given policy is. Ministries themselves may change their names or be newly created. In Ontario, the Ministry of Children and Youth Services (MCYS) was created in 2003. This Ministry's mandate is clear, but what is not clear is the extent of control this ministry has over the childhood disability programs that appear on its website, some of which are legal entities under legislation based in other ministries.

For example, the Ontario MCYS website states that the ministry administers the *Ministry of Community and Social Services Act*⁷⁸⁰ "insofar as it relates to activities and programs respecting children and youth services."⁷⁸¹ Yet, claims brought against the Ontario government respecting decisions under that *Act* are brought against the MCSS.

Who is legally responsible for what is not always clear, certainly not to many mothers. Thus, one may see that it is not only definitions and labels that pose challenges. So too, do the indeterminate and arbitrary aspects of the ministerial location and delivery of policy and programs as well as their legal underpinnings. This suggests that in Canada, policy for disabled children is understood to constitute health and social policy simultaneously, and, as a result of that, is treated as capable of being administered equally well in either domain. Yet, simultaneously, health, education, and social support are each housed in policy silos, a feature that calls upon one to question why. Location does not appear to be related to particular ministerial expertise or approach. In any event, ministers are moved around often⁷⁸² and ministerial expertise is not fostered, which reflects the bureaucratic model adopted across Canada. While bureaucrats, such as policy advisors, may remain in one area of government, they, too, may be moved around and are not placed in positions in which they are seen to have expert knowledge.⁷⁸³

These phenomena have bearing on the issue of transparency, which I address elsewhere. However, I note that much policy is not only dense and balkanized, as noted by Prince,⁷⁸⁴ it is also administered in ways unseen. This latter aspect is a flawed feature of child disability provisioning that has not gone without challenge. For example, lack of government transparency regarding an allocation of funding was the issue in the *Nieberg* litigation, the facts of which I discuss in Chapter Six. In *Neiberg*, the government did not provide reasons for its determination of low levels of support to two disabled children

⁷⁸⁰ RSO 1990, c M.20.

⁷⁸¹ Ontario Ministry of Children and Youth Services, "Results-Based Plan Briefing Book 2011-12", online: <http://www.children.gov.on.ca/htdocs/english/about/Results_2011-2012.aspx>.

⁷⁸² See Howlett, *supra* note 189.

⁷⁸³ This information was provided to me by a career policy advisor in the Ontario government.

⁷⁸⁴ A "complex, dense and overlapping sphere" is how he describes it. He also describes different policy fields. Prince, "Governance", *supra* note 437 at 390.

and their parents in need of it.⁷⁸⁵ Judicial review of provincial support determinations is not common, but the issues these reviews deal with may be.

The discussion thus far offers a brief critique of problems inherent in the present governance of supports to mothers with disabled children. It is understandable that under their weight, legal disputes arise. I now turn to discuss the provincial justice system, which many caregiving mothers ultimately engage with as they seek support.

Provincial Justice System

Forming part of Canada's system of justice, each province and territory has its own tribunals, boards and court system. Appeals from tribunals and boards dealing with the support issues of mothers with disabled children are heard in provincial, divisional, and appellate courts.⁷⁸⁶ However, prior to reaching that stage, each form of support has its own appeal process for decisions to be reviewed through the applicable provincial ministry.⁷⁸⁷ These are effectively "in-house" reviews of decisions by other bureaucrats.⁷⁸⁸ Although in the past, certain decisions could only be appealed internally, today, parents can appeal ministerial decisions respecting supports to provincial tribunals or boards.⁷⁸⁹ Examples would be the Ontario Social Benefits Tribunal (OSBT) and the Ontario Health Services Appeal and Review Board (OHSARB). Child protection applications in public law, private family law and in other civil matters are heard in the superior and provincial courts. Therefore, benefits such as provincial disability support for minors and age of majority disabled children, homecare determinations, and disputes relating to other support for children and their mothers may come before provincial tribunals, boards and courts for judicial review. Or, mothers may also sue in tort, or bring *Charter* claims, or they may sue for private support.

⁷⁸⁵ *Nieberg (Litigation guardian of) v Ontario (Minister of Community Family and Children's Services)* (2004), 70 OR (3d) 420, 238 DLR (4th) 73 [*Nieberg*, cited to OR]. The head note to this case lists entitlement to "Health and Social Services" as what the case is about. The parents were Jill Clough and Ryan Nieberg, both of whom have children stated in the decision to have severe disabilities. Their claims were for vastly high levels of support that they were accorded.

⁷⁸⁶ Disputes in respect of such things as the Child Disability Tax Credit would be to the Federal Tax court, not to provincial court. Likewise, federal pension and maternity leave matters with disability features may reach the Federal court after relevant board determinations.

⁷⁸⁷ As I note elsewhere it is unclear if, where, or how appeals were made to the Minister for refusals to provide a SNA. There is no case law that I could find. This is part of the mystery I refer to in my roadmap for this chapter.

⁷⁸⁸ See The OMCSS, *Guidelines*, *supra* note 755, that I was provided in 2001 described two levels of appeal from decisions as to SSAH funding. The First Level provided that the appeal had to be commenced within twenty days of the receipt of the decision from the Area Office. The Area Manager had twenty days in which to respond. The second level of appeal was again a twenty-day limitation in writing to the Assistant Deputy Minister, Program Management. A decision would be provided within twenty days. It states that, "Families can exercise their right to appeal at both levels once per application. The decision by the ADM is final and not appealable to a higher level." As seen in my research, appeals from SSAH decisions in Ontario may now go to the Social Benefits Tribunal.

⁷⁸⁹ *Ibid.* At one time, SSAH could only be appealed twice, both through the Ontario Ministry granting the benefit.

This situation presents as being far from a legally tidy or contained body of disputes.⁷⁹⁰ I turn now to describe three public support domains (homecare, provincial supports, and child welfare) and explain how each resolves legal disputes. I end with a description of a private avenue for support, family law. These examples illustrate what provincial disability support policy “looks like” in Ontario, Canada’s most populous province.

Provincial Support Offerings

Homecare

Homecare does not fall within “insured services” as defined in the *Canada Health Act (CHA)*⁷⁹¹ and the provisioning of homecare for children with complex medical care needs is dealt with provincially and territorially. Given the advent of a radically new form of childhood⁷⁹² experienced with severe impairments, it seems self-evident that a robust home healthcare system would be essential to mothers.⁷⁹³ Kiran Manhas has observed that there is no single definition for ‘homecare’ in Canada⁷⁹⁴ and that the fuzzy boundary around homecare makes describing or comparatively evaluating policy offerings across Canada very difficult. This difficulty is compounded when different terms for diverse forms of care are used interchangeably, when they may mean different things in government ministries. Another confusing example of this is that respite is often used as an adjective for a *form* of care but it is also to describe the break *from care* that the caregiver requires from providing continual home or complex care. Caregivers need respite from homecare provision, while those with complex care needs require respite care. Writing on the federal Health Canada website respecting care in the home, Janet Dunback states:

Home care is an increasingly important component of the health care system in Canada. As family caregivers play a growing role in providing care, their need for respite, or time off, is

⁷⁹⁰ Support policy is also messy. Provincial program names are different across provinces and territories. For example, the private domain of family law is not as private, nor separate, as it purports to be. Family law policy and practice has links to the public domain of adult social assistance and child welfare, as well as a range of benefit or assistance determinations. In Ontario, the Ontario Ministry of University Training, Colleges and Universities Ontario, which provides Ontario Students Assistance Plan loans to post-secondary students request disclosure of child support from mothers with whom the student more often resides, including disabled students. OSAP moreover does not seek disclosure of or include income information from separated fathers in calculations of loans to students being supported at home by their mothers.

⁷⁹¹ Jonathan Gray, “Homecare in Ontario: The Case for Copayments” (2000) 8 Health LJ 177 at 177. This means that mothers cannot sue Canada for not complying with the *CHA*, RSC 1985, c C-6 in the area of insufficiency of or quality of complex pediatric homecare.

⁷⁹² See Carnavale et al, “What We Know”, *supra* note 418 at 4.

⁷⁹³ “As the severity of disability increases, so does the need for assistive aids, help with everyday activities and home modifications. But as severity increases, so does the likelihood of unmet need for these supports.” This “includes human and technological supports.” L’Institute Roeher Institute, *Federal Transfer Options for Expanding Access to Disability Supports: – Summary Report* (North York, ON: Author, 2003) at 2 [Roeher, *Federal Transfer Options*]. This document was prepared for the CCD and CLA and while it may have been drafted with adults in mind, much of what it reports about need of support is also true for children and their mothers. This information was provided by Cameron Crawford.

⁷⁹⁴ Manhas, “Sufficiency of Home-Care”, *supra* note 182 at 279.

also growing. The purpose of respite is to give the caregiver a break in order to avoid burnout or crisis, to enable the caregiver to take care of necessary activities outside the home, and to support a healthy relationship between the person receiving care and the caregiver. Respite can also provide a break for the person receiving care.⁷⁹⁵

This description refers to respite as both a break for the caregiver and a break for the cared for. It also notes that respite is provided in the service of crisis management. Thus, Health Canada acknowledges the reality of crises for caregivers who do not receive relief. Writing in the United Kingdom, Clare Burns describes respite for severely disabled children as the provision of relief and support.⁷⁹⁶ Her definition is more encompassing than is Health Canada's, and includes longer stays in hospitals, temporary foster care, family-based short breaks, and residential care as needed. Mary Mather refers to British research demonstrating that sixty percent of families with severely disabled children spend over ten hours daily providing essential care, and fifty percent as providing twenty-four hours a day of care.⁷⁹⁷ This information shows that different forms of care fall under the label of 'homecare' and that such care ought to be measured consistently in order to be properly provided for in public policy.

I next provide the example of Ontario to illustrate one provincial circumstance of support policy to disabled children cared for at home.

Ontario Homecare Provisioning

In Ontario, mothers may apply for medically-oriented care to be provided at home through The Ministry of Health and Long Term Care (MOHLTC). In 1996, this Ministry delegated its control over homecare management and allocation to Community Care Access Centres (CCACs).⁷⁹⁸ The purpose of the CCACs was to assist people with their applications for and allocation/arrangement of home care for homecare

⁷⁹⁵ Janet Dunback, "Respite for Family Caregivers: An Environmental Scan of Publicly-funded Programs in Canada" (Ottawa: Health Canada, 2003) online: Health Canada <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2003-respite-releve/index-eng.php#a3_9> at 1.

⁷⁹⁶ Clare Burns ed, *Disabled Children Living Away From Home in Foster care and Residential Settings* (London: MacKeith Press, 2009). According to Jennifer Cousins, *Every Child is Special: Placing Disabled Children for Permanence* (London: British Association for Adoption and Fostering, 2006) at 10, 40% of "the most severely and multiply disabled children" in the UK are in foster care.

⁷⁹⁷ Mary Mather, "Invisibility, Disability and the Problems of Public Care" in Burns ed, *supra* note 796, 15 at 27.

⁷⁹⁸ Until late 2016, centres assisted with access to government funded community homecare in the community. See Ontario Ministry of Health and Long-Term Care, *Community Care Access Centres: Client Services Policy Manual*, no longer available online [MOHLTC, "Client Services Policy Manual"], Chapter 3 of the manual is reproduced in my MRP, Sheila Jennings, *Paediatric Home Care of the Child with Complex Care Needs in the Context of Human Rights and Provincial Experiences* (Masters Research Paper, York University Graduate Program in Critical Disability Studies, 2010) [unpublished, archived personally]. This time frame corresponds with a range of privatizing health care measures undertaken in Ontario.

services and with independent living.⁷⁹⁹ This included mothers requiring nursing care for children, including their adult severely disabled children over age 18.

In 2016, a new approach was implemented to oversee the delivery of healthcare, one that included homecare to disabled children and their mothers. The Local Health System Integration Network (LHIN) purports to improve patient access.⁸⁰⁰ For example, there are patient and family advisory committees to improve community engagement.⁸⁰¹ It aims to integrate all CCAC's into one organization with the stated aim to meet the objectives of new legislation.⁸⁰² Like the CCAC system, there is a Patients Bill of Rights. It remains to be seen how it will perform in the case of medically disabled children and youth and whether it is more or less accountable to caregiving mothers.

In addition to homecare, in the case where a child needs a very high level of care, the regionally relevant CCAC provided care through its *Enhanced Respite for Families Caring for Medically Fragile and/or Technology Dependent Children at Home*.⁸⁰³ At the time of writing, the MOHLTC website had a table showing which sorts of childhood conditions may qualify to receive the grant of \$3,500 a year for this so-called enhanced respite for children under eighteen who require twenty-four hour a day care in order to survive.⁸⁰⁴ Examining the mathematics, \$3,500 divided by \$30 (roughly the hourly rate for a personal support worker) offers about 116 hours of enhanced respite a year, which is less than the 168 hours in one week, all of which hours must be covered vigilantly, primarily by mothers, in such cases.⁸⁰⁵ As Health Canada notes,⁸⁰⁶ and as the case law I examine brings to light, even if enhanced respite services were available in a greater number of client hours (which is unlikely in current approaches to support policy), there are not enough qualified healthcare personnel to meet needs. At least, there are not enough qualified homecare nurses who were given contracts by CCAC's.

⁷⁹⁹ The use of the word "independently" is informative here. It means with the support of family and that family is usually a woman.

⁸⁰⁰ See Ontario Ministry of Health and Long-Term Care, "Ontario Introduces New Legislation to Further Improve Patient Access and Experience", (Toronto: Author, 2016) online: MOHLTC <<https://news.ontario.ca/mohltc/en/2016/06/ontario-introduces-legislation-to-further-improve-patient-access-and-experience.html>>.

⁸⁰¹ *Patient First Act 2016, S.O. 2016, c.30* at subheading Patient Advisory Committee.

⁸⁰² *Patients First Act, supra* note 801.

⁸⁰³ *Ibid.*

⁸⁰⁴ No longer available online. CCACs are no more and have been made into LIHNs.

⁸⁰⁵ The Registered Nurse Association of Ontario stated that Ontario has the second lowest ratio of nurses per capita in Canada. They state continued cuts places patients at risk. See Trevor Koroll, "Ontario Faces Potential Nurse Shortage: While Most of the Country Saw an Increase in the Number of Registered Nurses per Person between 2008-2023, Ontario's Numbers are Falling", *The Varsity* (21 October 2013) online: The Varsity <<http://thevarsity.ca/2013/10/21/ontario-faces-potential-nurse-shortage/>>.

⁸⁰⁶ See Janice M. Keefe & Marlie Manning, "The Cost Effectiveness of Respite: A Literature Review" (Ottawa: Health Canada, 2005) online: Health Canada <<http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2005-keefe/index-eng.php>>. In the section entitled "Respite Care for Caregivers of Children with Complex Care Needs," Keefe and Manning refer to Canadian research that found families were "heavily burdened" by inadequate state respite provisioning. See also *LS, supra* note 359, in which the CCAC was unable to meet the approved PCCAC nursing hours of an eligible mothers with a severely disabled daughter.

It remains to be seen whether this feature will improve under the new LHIN. This situation translates into substantial unmet need. The CCAC website I examined prior to the commencement of the LHIN system did not offer complete information, stating (as it has for the past several years) that, “[t]he addition of a fifth category of care [medically fragile children who do not use technological devices] was made in a February 15, 1999 memorandum sent to CCACs from the Office of the ADM, Office of Integrated Services for Children (OISC).”⁸⁰⁷ It also provides:

It is recognized that aspects of the eligibility criteria for Enhanced Respite funding would benefit from additional clarification. Such requests most often are related to the Group V category, children who are medically fragile according to the care requirements but who do not use a technological device.⁸⁰⁸

This long-acknowledged (by the MOHLTC itself) incomplete information is indicative of the *unfinished nature* of such policy offerings.⁸⁰⁹ An example of this is offered by the section of the MOHLTC CCAC website for parents that did not clearly state what is to take place when a child turns 19, or why the needs of a 19 year-old who is severely disabled and requiring enhanced respite care at home are any different from an 18 year-old in this same situation (in provinces where the service cut off is 18).⁸¹⁰ Complicating matters, there is more than one form of ‘home’ care offered throughout the provinces. There are several forms of respite care for example, some of which are to be provided in the child’s home and some in another person’s home, which, in Ontario, are dealt with as a social benefit provided under a different Ministry (MCYS). Respite care is dealt with more as social care than medically-oriented care, but in reality, the line may be blurred.⁸¹¹ Where mothers require more homecare than the state presently

⁸⁰⁷ See MOHLTC, “Client Services Policy Manual”, *supra* note 798 at s 3.10.4. I suspect even with this addition the list is incomplete and does not account for all medically fragile or technology dependent children. For example, none of the MOHLTC boxes setting out conditions met by the various groups covered mention chronic at-home nebulizer machine use for children with severe asthma. Yet, the Enhanced Respite Program is mentioned on the discharge checklist in Mary Bayliss et al, “A Continuum of Care From Hospital to Home – A Training Manual for Pediatrics & Adults” (Toronto: The College of Respiratory Therapists of Ontario, 2010) online: St Michael’s Hospital <<http://www.stmichaelshospital.com/pdf/crich/sru-respiratory-therapy-manual.pdf>>. I discuss the serious problem non-comprehensive childhood disability policy in the context of American litigation and policy research elsewhere.

⁸⁰⁸ MOHLTC, “Client Services Policy Manual”, *supra* note 798 at s 3.10.4.

⁸⁰⁹ This is not only an Ontario concern and it is a concern with broad implications. Manitoba researchers in a recent publication that reports on a study of parents of children with complex care needs participation in society, in their conclusion ask whether society will be there to assist families with children with severe disabilities (complex care needs is the term they use). See Woodgate, Edwards & Ripat, *supra* note 358 at 1919.

⁸¹⁰ Thus, approaching or attaining the age of majority poses a threat to caregiving mothers and severely disabled children both. The only option for “care” may be a nursing home. Youth as young as 17 have been placed in such facilities. See for example, Lisa Priest, “Nursing Homes No Answer for the Young” *Globe and Mail* (December 18, 2004) online: <http://www.theglobeandmail.com/news/national/nursing-homes-no-answer-for-the-young/article1008752/?page=all>>.

⁸¹¹ See for example *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, SO 2008, c 14. To be eligible for this funding an applicant pursuant to s 14(2)(b) a person must be

provides, they must pay for it. Respite for a severely disabled child in Ontario can cost upwards of \$2000 a week.⁸¹² Like lawyer-mothers in BC protesting the lack of affordable daycare spaces, I suggest that this is a human rights issue.⁸¹³

Social Benefits

Mary Jane Mossman and Morag MacLean note the relatively recent arrival of social assistance programs in Canada. In addition to other social welfare schemes, in 1966, the Canada Assistance Plan (CAP) was put into place wherein the federal government funded half of the costs of social welfare programs across Canada.⁸¹⁴ Later, as noted above, the federal government placed a cap on the CAP. And thirty years later, the federal government changed this scheme, also noted above, and provinces responded by making deep cuts to social programs, funding and benefits previously in place to support marginalized and at-risk groups of people.⁸¹⁵

Social programs are typically described as benefits. Each province and territory offers support to severely disabled children and their mothers through a range of these. Some of those I researched in 2013 are undergoing change. However, the fundamental thrust of the policy has not changed. The 1991 Ontario Special Services At Home respite policy guidelines that I was provided by the Ontario government, when it approved my application in 2002, stated that respite was “initiated in 1982 to help CHILDREN with DEVELOPMENTAL DISABILITIES to live at home with their families and to prevent their institutionalization.”⁸¹⁶ The program was not initiated such that the previously available around-the-clock care provided and funded by large state institutions to those under-resourced mothers would be provided

at least 18 and the funding is discretionary, by way of an agreement. This *Act* permits the Ministry to put in place policy Directives and rules in respect of how services and supports are delivered. The Ontario website provides that policy guidelines are available to all, see Ontario Ministry for Community and Social Services, “Policy Directives for Application Entities” online:

<http://www.mcscs.gov.on.ca/en/mcscs/publications/developmentalServices/policy_application/toc_directives.aspx>.

⁸¹² I found it surprisingly difficult to access details concerning cost of residential respite. Darling House had a dead link to the Ontario government’s Enhanced Respite program, Reena’s place stopped returning my calls, and there was notification of waitlists where one might expect to find important financial information at another centre’s website. Some examples of respite facilities in Ontario are Darling House, Holland Bloorview, Emily’s House, Safe Haven and Reena’s place. One Ontario caregiving mother told me all respite today carries a fee.

⁸¹³ See David Ball, “Child Care Shortages Costs, ‘A Human Rights Violation’: Law Report” *Metro* (12 July 2016) online: <<http://www.metronews.ca/news/vancouver/2016/07/12/childcare-shortages-costs-a-human-rights-violation.html>>.

⁸¹⁴ Mary Jane Mossman & Morag Maclean, “Family Law and Social Assistance Programs: Rethinking Equality” in Patricia M. Evans & Gerda R. Wekerle eds, *Women and The Canadian welfare State: Challenges and Change* (Toronto: University of Toronto Press, 1997) 117 at 126.

⁸¹⁵ The results of such cuts are examined throughout Martha Jackman & Bruce Porter, eds, *Advancing Social Rights in Canada* (Toronto: Irwin Law Inc, 2014). Barbara Cameron, “Accountability Regimes for Federal Social Transfers: An Exercise in Destruction and Reconstruction” in Jackman & Porter, *ibid*, 129, at 129-130 states “With the elite retreat from Keynesian welfare State, the destructive possibilities were apparent in the unilateral reductions by the federal government in the amounts transferred to the provinces and the weakening or outright elimination of the conditions attached to funds.”

⁸¹⁶ OMCSS, *Guidelines*, supra note 755. (Emphasis in original.)

at home.⁸¹⁷ Rather, “individualized consumer-directed funding” would “modify” “mainstream services” to assist “families.” The statement made was that “Special Services at Home has successfully supported children to live as independently as possible with their own families in their own communities.”⁸¹⁸

In Ontario, as noted above, the Ministry of Children and Youth Services (MCYS), Ministry of Community and Social Services (MCSS), Ministry of Health and Long-Term Care (MOHLTC), and the Ministry of Education are the government bodies dealing with the provision of disability support programs and funding, health, home care, child welfare.⁸¹⁹ The MCYS website explains that access to programs and services for children with “special needs” is through regional offices. The website at the time of writing has divided services and funding information into four areas: autism, developmental disabilities, disabilities, and mental health. These divisions are somewhat confusing, in part, because they do not correspond with diagnostic measures or the “special” needs of these children. Moreover, many children have dual or multiple diagnoses.

The website has three portals for the areas of Rehabilitation, Respite, and Special Services at Home (SSAH).⁸²⁰ By Respite the MCYS refers to two programs. One is for out-of-home overnight care for children who require twenty-four hour a day care and supervision for children with multiple disabilities or developmental disabilities, and the other is for enhanced respite with eligibility restricted to children with severe medical conditions that also require 365 day a year care and who may use technology in order to survive.⁸²¹

SSAH was, in the current era, stated to exist to fund a caregiver to provide Respite for a child with a disability or developmental disability whose parents “need more support than most families can provide,” and set up to “enhance” the capacity of the caregiver.⁸²² SSAH assistance allows a child to

⁸¹⁷ The 1982 date corresponds with deinstitutionalization, with changes to the Ontario *Child and Family Services Act*, RSO 1990, c C.12 [*CFSA*], and to the move towards privatization of care. Critiques of institutions that housed disabled children are manifold, but often omit a class or gender lens. Perhaps this is because critiques have been presented primarily by white men and by white married middle and upper middle class women, at least in Canada. Those “bad” mothers who institutionalized their disabled children often needed, but did not have, adequate support. The body of work of Veronica Strong-Boag gets this across well. See Strong-Boag, *Fostering Nation?* *supra* note 350. She comments that parents have regularly used institutions to manage crises, irrespective of disability. She is a critic of women being disproportionately responsabilized with care of children, disabled or not, with the suggestion that institutions were an outcome of such societal expectations.

⁸¹⁸ Questions arise from this, such as, on what basis was the program’s “success” measured, and what family form was envisioned?

⁸¹⁹ As well as special education policy for children with disabilities.

⁸²⁰ In 2008-2009, 63% of the 27,399 people in respect of whom SSAH services were provided were children with disabilities. Statistic provided by Cameron Crawford.

⁸²¹ These portals do not indicate that the MCYS actually administer these supports. Enhanced respite is through the MOHLTC.

⁸²² Eligible persons include children, youth, and adults who have developmental or physical disabilities who meet program requirements. See OMCSS, *Guidelines*, *supra* note 755.

remain in a program, provides care, guidance and personal safety, and supports the child in learning activities.⁸²³

Regardless of changes in program names, there are waiting lists in Ontario for respite, and a child may ‘age-out’ of eligibility while on the list. One reason for this may be that the MCYS remains underfunded.⁸²⁴ In 2000, a paper was published by the Ontario Ministry and others interested in seeing higher levels of respite, entitled *Increasing Planned Out of Home Care For High Needs Multiple Special Needs Children with Developmental And/Or Physical Disabilities Living At Home*. The context of this paper was “problems with the current status of respite care for children with disabilities in general as well for children with specific disability related needs including medically fragile and technology dependent children with complex medical needs and children with Acquired Brain Injury.”⁸²⁵ This document was written with the forgone conclusion that the respite needs of children with multiple special needs were not being met. Its stated aim was to assist government and regional respite stakeholders to put in place funding to increase out of home respite.⁸²⁶

Government is aware of the shortfalls. Some provincial programs provide small amounts of funding at intervals to parents with severely disabled children up to age 18. The Assistance for Children with Severe Disabilities Program (ACSD) in Ontario is one example. Section 40 of the *Ontario Disability*

⁸²³ This data was gathered for the unpublished and incomplete draft manuscript, Sheila Jennings & Cameron Crawford, “Who Cares? Continuing Disputes in the Public Sphere as to Support for Children with Severe Disabilities in Canada” (2011) [unpublished, archived personally]. Though not mentioned on the Ontario Ministry website, Nursing Respite may also be provided under this provision. Special Services at Home Provincial Coalition, *Latest statistics for 2008/09 received summer 2009* [no longer available online]. One thing that has become apparent over the course of my research is, is that what is or was available in Ontario policy is not obvious. Previously informed mothers could try to access enhanced funding through Orders in Council. Advocate and litigator Marilyn Dolmage told me this in 2010. In *Nieberg, supra* note 785, it is stated that in 2001 “additional money” was allocated by government to pay for services for special needs children, including the litigant children, though clearly it was insufficient. It is not clear what this additional refers to exactly, whether it was a top up of SSAH, ACSD or something else.

⁸²⁴ Aging out is one problem, categorizing disabled people based on age is another. Having an 18 year old “child” with developmental disabilities in one’s care is practically speaking often no different than providing services to a 19 year-old “adult” in one’s care. However, in ironically normative policy offerings they are dealt with very differently. Developmental Services in Ontario provides a program to those with a developmental disability over age 18 to participate in their communities. See the Ontario government’s Developmental Services program offerings, Ontario Ministry of Community and Social Services, “Help with Daily Living” (Toronto: Queen’s Printer for Ontario, 2012) online:

<<http://www.mcscs.gov.on.ca/en/mcscs/programs/developmental/servicesupport/passport.aspx>>.

⁸²⁵ Ontario Ministry for Community and Social Services, *Increasing Planned Out of Home Care For High Needs Multiple Special Needs Children with Developmental And/Or Physical Disabilities Living At Home: Implementation Guidelines* (Toronto: Queen’s Printer for Ontario, 2000) at 2. Footnotes reveal studies in the 1990s, including those aimed to address Ontario regions, such as Metropolitan Toronto District Health Council. See *Strategic Plan for Children with Long Term Care Needs in Metro Toronto* (Willowdale: Author, 1997) and nationally oriented studies such as Virginia E. Hayes, *Services for Children with Special Needs in Canada – A Report Prepared For The Canadian Association of Community Care and Health Canada* (Ottawa: Canadian Policy Research Networks, 1997).

⁸²⁶ *Ibid* at 5.

Support Program Act 1997 allows for support to children who have disabilities and whose parents incur unusual costs. The program provides from \$25 to \$430⁸²⁷ a month to help cover costs.⁸²⁸ In April 2011, 24,849 children in Ontario were receiving ACSD.⁸²⁹ Eligibility and support are dependent on such things as family income and the child's disability. It is unclear how the quantum of support is arrived at. It is not a transparent system and it sometimes awards ridiculously low amounts,⁸³⁰ including as little as \$25 a month state support for a girl with Di Georges Syndrome.⁸³¹ One disability advocate advised that quanta of support for funding amounts on offer through this program are likely a "back of the envelope" determination that policymakers decided was suitable.⁸³² Caregiving mothers whose economic viability depends on state supports require much more accountability than this.

Each province has disability income support for adult disabled children. In Ontario, those over age 18 can seek income support through the Ontario Disability Support Program (ODSP) on their own, or with help. Other provinces offer income support, and amounts vary. In Alberta, the amount is higher than in Ontario. In fact, media has reported on discrepancies in disability supports across Canada.⁸³³ Also, in relation to older teenagers with disabilities and adults, until recently, Developmental Services of Ontario (DSO) agencies served adults with developmental disabilities over the age of 18. Its stated aim is to help caregivers of developmentally disabled persons have respite from care.⁸³⁴ This support provision has been silent on the issue of *income* support to caregivers.⁸³⁵ The DSO website had a notice in February 2014 that funding was under review, which, as noted, is a continual feature of such policy.

⁸²⁷ Amounts awarded are subject to appeals at the Ontario Social Benefits Tribunal and from there to the provincial court.

⁸²⁸ These are to help pay for such things as travel for medical care; clothing; respite; wheelchair repairs; assistive devices, medication and glasses.

⁸²⁹ Ontario Ministry of Community and Social Services, *Ontario Social Assistance Monthly Statistical Report: Ontario Disability Support Program* (Toronto: Author, 2011), no longer available online [OMCSS, *Statistical Report*].

⁸³⁰ It is understood that there are policy guidelines used by officials to gauge support entitlement, however much is unknown about how such determinations are made, whether they are applied consistently or reviewed.

⁸³¹ Once the cost of a postage stamp and TTC fare to and from the bank are accounted for there would be approximately \$17 left with which to support one's child. Di Georges Syndrome is a serious chromosome 22 condition that involves the functioning of the heart and the immune system, as well as having other medical features.

⁸³² What factors went into the process to determine amounts are not known to me. The individual in question has asked to remain anonymous.

⁸³³ Under the Assured Income for the Severely Handicapped (AISH) a single disabled person in Alberta in 2012 reportedly received \$1,588 a month, six times what a family of six receives in British Columbia. See Katie Hyslop, "Jump in Alberta Disability Benefits Leave BC Far Behind", *The Tyee* (15 February 2012) online: The Tyee <<http://thetyee.ca/News/2012/02/15/Disability-Benefits/>>.

⁸³⁴ Funding assists with hiring a support worker, respite, and life skills.

⁸³⁵ See MOHLTC, "Client Services Policy Manual", *supra* at note 798.

The Ontario government also funds agencies that offer people with developmental disabilities housing, including to disabled teenagers.⁸³⁶ Options listed are group homes, host-family homes, specialized accommodation, supported independent living and individualized residences.

There is some overlap between DSO and SSAH in Ontario, for example, the Host Family Respite Program was featured under both DSO and SSAH. DSO reported two years ago that “funding entities” are being created. In addition to allocating funds, these programs manage referral for supports and provide “support and assistance”⁸³⁷ to those on government wait lists.⁸³⁸

In spite of what the government websites offer, the situation for disabled youth in Ontario remains dire.⁸³⁹ They are also very complex to negotiate. This means that many caregiving mothers in serious need of supports for disabled children or youth struggle. Some of these eventually resort to child welfare agencies for care supports.

Child Welfare

Child welfare refers to provincial and territorial services for children and families. Child welfare has historically been heavily involved in providing services to disabled children,⁸⁴⁰ and every province and territory has its own child welfare regime and accompanying legislation. The mandates of agencies are to support family stability through consensual measures, and to protect children at risk of maltreatment. Agencies can bring applications to court to apprehend children, and may ask a judge to make them temporary or crown wards of the state. Even though services may be provided voluntarily, the focus in child welfare is on child protection, which is a legal domain. When agencies bring child protection applications to court, applications fall under provincial, and judicial *parens patriae*, jurisdiction. *Parens patriae* doctrine has to do with the state’s obligation to ensure the welfare of children. It requires that child welfare agencies and courts consider the needs of the minor or vulnerable persons before the court. Courts will either employ substitute decision-making or consider the best interests of the child respectively. In the child welfare context *parens patriae* usually applies to the state stepping in where parents have abandoned, been negligent, or who have been abusive to a child.

However, the ability of a child welfare court to make a decision that is in the best interests of the *severely* disabled child in the current approach to state funded out of home care has not been closely

⁸³⁶ “Offer” is the word used on the DSO website, “Residential Services and Supports” (August 2016) online: <<http://www.dsontario.ca/residential-services-and-supports>>.

⁸³⁷ Developmental Services Ontario. “Waiting Lists/Prioritization” (July 2014) online: <<https://www.dsontario.ca/waiting-lists-prioritization>>.

⁸³⁸ Until such entities are created, DSO agencies have responsibility to assist people in “most urgent need” of services and supports. *Ibid.* Note DSO and SSAH programs have been repeatedly reformulated.

⁸³⁹ Ontario MPP, the honourable Christine Elliott, was instrumental in bringing about the Select Committee on Developmental Services. *Select committee, Interim Report*, *supra* note 650.

⁸⁴⁰ See Strong-Boag, “Children of Adversity”, *supra* note 369. This is discussed throughout her article.

examined. I argue that some provincial court judges have been constrained by what they believe they should be able to do (Justice Anne Molloy in *JMS*, for example)⁸⁴¹ or are unwilling to decide in the best interests of the disabled child, due to fears about interfering in the policy role of government (Ontario Court of Appeal in *Larcade*).⁸⁴² *Obiter dicta* in some decisions, suggests that judges are being required to adjudicate medical/health cases, as though they are child protection or domestic cases. In such cases, child welfare might learn from the health law literature.⁸⁴³ A point to consider is whether “under the aegis of *parens patriae*, actions which may be sanctioned as parental in purpose are in reality, less wholesome in effect.”⁸⁴⁴ To be ‘wholesome’ severely disabled children’s needs have to be the priority in child welfare decisions.

Deborah Weimer, examining best interests of children with HIV unable to access certain treatments because of American foster care laws, argues that Best Interests of the Child is a vague standard. Although she is arguing specifically in relation to consent to medical treatment, the factors she suggests need to be taken into consideration in the determination of best interests of a severely ill child should be of interest. These are: priority given to the person most likely to advance the child’s interests; those intimately involved with the day-to-day care of the child to have a major role in decision making; someone knowledgeable about the child’s condition to be involved in the decision making; and involvement of someone who can comprehensively and impartially look at all the facts.⁸⁴⁵ The caregiving mother would fall into three of the four areas, yet in current practice she is positioned as adverse and as a non-expert.

The institutional belief in child welfare systems has been that disabled children burden parental capacity.⁸⁴⁶ The institutional response to this is the perceived need of increased supports, particularly to mothers. Where severely disabled children are concerned, one of these, in Ontario, was the Special Need Agreement (SNA). The SNA allowed shared care between the province and a parent of a severely disabled child. The SNA allowed the parents to have continued involvement in their disabled children’s

⁸⁴¹ *J.M.S. supra* note 15.

⁸⁴² *A.L. v Ontario (Minister of Community and Social Services)* (2006) 83 OR (3d) 512, 274 DLR (4th) 431 (ONCA).

⁸⁴³ See for example discussions in Deborah Weimer. “Beyond Parens Patriae: Assuring Timely, Informed, Compassionate Decisionmaking for HIV-Positive Children in Foster Care” (1991). 46 *University of Miami Law Review* 379.

⁸⁴⁴ George B. Curtis. “The Checkered Career of Parens Patriae: The State as Parent or Tyrant?” (1976). *DePaul Law Review* 25:4, 895 at 895.

⁸⁴⁵ Weimer *supra* note 843 at 391

⁸⁴⁶ See PHAC, “Canadian Incidence Study”, *supra* note ##. Karen Aniol et al, in a preliminary investigation, recommend interventions, including respite care, to target variables that relate to maltreatment, such as parental stressors. They also advocate further inquiry into the presence of a relationship between inadequate respite and disabled child maltreatment, an issue contested by a few Canadian disability rights advocates. The latter however are not experts in child protection. Karen Aniol et al, “The Relationship between Respite Care and Child Abuse Potential in Parents of Children with Developmental Disabilities: A Preliminary Report” (2004) 16:3 *Journal of Developmental and Physical Disabilities* 273.

lives and they remained the legal parents. A child could be placed into state care (specialized foster care or other care arrangement). Agreements for care were time limited, but could be renewed at the discretion of the government or director of the child welfare society. The SNA was supportive of the child welfare agency mandate, to keep families intact, something that is in the best interests of the child, which is itself the paramount purpose of the governing legislation.⁸⁴⁷

Another voluntary support option to families with non-disabled and disabled children alike is a voluntary agreement, in which agencies monitor the child at home, and offer targeted community supports. Supports however are often extremely limited. This agreement is often arranged through a family lawyer and is time-limited. Such agreements are not uncommon in cases where an agency has some concerns, but where concerns do not rise to the level of a perceived need to take the disabled child into care.

As noted with respect to other provincial support offerings, there is variability as to how provinces provide child welfare services to those requiring help. For example, at one time, Alberta provided services to families with severely disabled children through that province's child welfare system. This involved having parents consenting to place their disabled child in specialized foster care. In 2004, Alberta's *Child, Youth and Family Enhancement Act*⁸⁴⁸ came into force, replacing the law under the *Alberta Child Welfare Act* and regulations. Also in 2004, the *Family Support for Children with Disabilities Act* became law, with Alberta being the first province to enact childhood disability legislation that, on its own, provided support to families with disabled children, and was legally separate from the former child welfare legislation.⁸⁴⁹ Alberta also has programs for disabled children in Health and Wellness (MHW) and Children and Youth Services ministries. It is notable that the preamble to the 2004 *Alberta Family Support for Children with Disabilities Act* promotes disability rights in keeping with the *CRPD* and *CRC*.⁸⁵⁰ I mention these to draw attention to the awareness of international law of some provinces' lawmakers.⁸⁵¹ With the exception of Quebec, and more recently Alberta, statutes providing

⁸⁴⁷ Ontario mother Anne Larcade entered into a special needs agreement with the Ontario government for her son Alexandre. When the government ended the agreement she sued. *A.L. supra* note 207.

⁸⁴⁸ RSA 2000, c C-12.

⁸⁴⁹ See Milena Christopher, "Family Law: Children, Families and the Law" (2005) 29:5 *LawNow* 45.

⁸⁵⁰ *Samantha's Law*. See Alberta legislation at Appendix G. *Family Support for Children with Disabilities Act*, RSA 2003, c F-5 3.

⁸⁵¹ There is also in Manitoba, the *Child and Family Services Authorities Act*, RSM 2008, CCSM c C90. This legislation is administered by the Ministry of Manitoba Family Services. This Act oversees the services of First Nations child welfare agencies with a stated goal to provide services consistent with the *Child and Family Services Act*, RSM 2015, CCSM c 80 [Manitoba, *CFSA*]. Nova Scotia has a *Children and Family Services Act*, SNS 1990, c 5 through its Ministry of Community Services. British Columbia has its *Child, Family and Community Services Amendment Act*, RSBC 1996, c 46, in the Ministry of Children and Family Development. The Ontario *CFSA* governs programs and services in the Ministry of Children and Youth Services. Quebec has its *Youth Protection Act*, RSQ 2015, c P-34.1, under the Code Civile in the Quebec Ministry of Health and Social Services.

services to disabled children are much the same in terms of title of *Act*, child welfare society organization, structure and mandates.⁸⁵² For example, Manitoba has a Voluntary Placement Agreement not unlike that of Ontario's SNAs. Section 14(1) of Manitoba's *Child and Family Services Act*⁸⁵³ has a provision for voluntary placement of a child with an illness, mental disability or "with a chronic medical disability requiring treatment which cannot be provided if the child lives at home."⁸⁵⁴ In this case, support is offered through a twelve-month agreement for care to be provided in foster homes and other residential settings. Nova Scotia also offers service agreements through similar legislation.

Provinces and territories also have limited residential care offerings, some defined as treatment.⁸⁵⁵ Residential offerings do exist for children found in need of protection. For disabled children, there is specialized foster care, and institutional care. Disabled children are represented in state care at significantly higher rates than non-disabled children.⁸⁵⁶ There were reportedly 9,199 disabled child wards in the care of Ontario's Children's Aid Societies in 2007-2008, which translates as sixty-eight percent of Crown wards having "special needs, for example, learning disabilities, attention deficit and/or hyperactivity disorder, psychiatric, developmental disability."⁸⁵⁷

In Ontario, government-funded children's treatment centres have lengthy wait lists and some have faced closures.⁸⁵⁸ Other provinces and territories also run "homes" for treatment or care as well. All

⁸⁵² Saskatchewan offers services to children with disabilities through their *Child and Family Services Act*, RSS 2014, c C-7.2.

⁸⁵³ Manitoba, *CFSA*, *supra* note 851 s 14(1).

⁸⁵⁴ In Manitoba "Children's Programs is responsible for the administration of the sections of *The Child and Family Services Act* that address the needs and rights of children with disabilities in care. A broad range of high-quality social services is available which are designed to strengthen and support families of children with disabilities". Manitoba Family Services, "Children in Care with Disabilities", online: <http://www.gov.mb.ca/fs/pwd/children_in_care.html>. Pursuant to Manitoba, *CFSA*, *supra* note 851, s 14(1), which provides for voluntary placement: "An agency may enter into an agreement with a parent, guardian or other person who has actual care and control of a child, for the placing of the child without transfer of guardianship in any place which provides child care where that person is unable to make adequate provision for the care of that child (a) because of illness, misfortune, or other circumstances likely to be of a temporary duration; or (b) because the child (i) is a child with a mental disability as defined in *The Vulnerable Persons Living with a Mental Disability Act*, or (ii) is suffering from a chronic medical disability requiring treatment which cannot be provided if the child remains at home, or (iii) is 14 years of age or older and beyond the control of the person entering into the agreement."

⁸⁵⁵ This does not mean that they are necessarily available.

⁸⁵⁶ See Ontario Ombudsman, *Between a Rock and a Hard Place*, *supra* note 187.

⁸⁵⁷ Information provided by Cameron Crawford, accessed from Ontario Association of Children's Aid Societies, *2010 – 11 pre-budget consultation: Submission to the Standing Committee on Finance and Economic Affairs* (Toronto: Author, 2010).

⁸⁵⁸ Personal knowledge gained from my own child welfare practice. Thistletown Regional Centre serves, amongst others, individuals with severe PDD and autism. In the Ontario Ministry for Children and Youth Services, News Release, "Improving Mental Health Services for Children and Youth" (19 March 2012), the Ministry stated that services were being taken over by community based mental health services as this was closer to the homes of clients and better served their needs. These provide services to over 58,000 children and youth per year who have moderate to severe disabilities (and other needs). With the threatened closure of Thistletown, parents of individuals with autism and PDD stated to media that they would complain to the Ombudsman. See Valerie Hauch, "Thistletown's

provincial and territorial legislation has provisions permitting a court to find a child in need of protection. Grounds for such findings include children at risk of abuse or neglect. However, they also operate as a result of legal findings of abandonment, where no abandonment exists.⁸⁵⁹ The conflation of need of disability supports in childhood with child maltreatment in child protection schemes is addressed below as a central feature of mother's legal right to support.

State Custody as Support

It is unclear to what extent mothers in provinces and territories across Canada are relinquishing custody of their severely disabled children in exchange for care. This is an under-researched area, lacking data. As a matter of legal practice, this phenomenon has been subjected to a closer legal examination in the American literature than it has in Canadian literature. Indeed, in a Canadian publication, legal scholar Gwen Goodman states that “the problem of custody relinquishment is difficult to address because there has been little litigation on the issue”, and she suggests that it might be challenged as an unconstitutional or discriminatory practice.⁸⁶⁰ Goodman's statement is relevant to several cases discussed in my thesis. Concerns in respect of custody loss of disabled children were brought to light by the Ontario Ombudsman and in media in an Ontario provincial court case in the late 1990s. At that time, Ontario⁸⁶¹ is alleged to have sent a directive to provincial child welfare agencies to cease entering into SNAs pursuant to s 30 of the *CFSA*, which used to allow shared care between the province and the parent⁸⁶² of a severely disabled child.⁸⁶³ Section 30 has since been repealed, and is no longer used by Ontario.⁸⁶⁴ But prior to its repeal, a policy void came into being when Ontario decided not to engage with the section. The provision of this form of voluntary support for care by the state is thus no longer an option. In its place, privatizing measures, like the ACSD through the MCSS, the Enhanced Respite program through MOHLTC and other

Scheduled Closure Stressful Time for Parents” *The Star* (15 October 2012) online: [The Star <http://www.thestar.com/news/gta/2012/10/15/thistletowns_scheduled_closure_stressful_time_for_parents.html>](http://www.thestar.com/news/gta/2012/10/15/thistletowns_scheduled_closure_stressful_time_for_parents.html). There was also a petition circulated and media coverage of the controversial closure. The MCYS website for 2013 reported increased funding to children's treatments centres in Northern Ontario to fund information networks and more access to IBI therapy. Services at such centres also may include physiotherapy, occupational therapy and speech and language therapy.

⁸⁵⁹ See s 37 of the prior *Child and Family Services Act*, RSO 1990, c C.11, for the example of Ontario. I address why the finding of abandonment is problematic later in the dissertation.

⁸⁶⁰ Gwen Goodman, *supra* at note 184, at 303.

⁸⁶¹ The Ontario government admits there was a Directive, but was unable to produce the Directive itself in the *Larcade* (2003), litigation, as noted at para 22 of the 2003 decision. *L (A.) v Ontario (Ministry of Community and Social Services)* 65 O.R. (3d) 289 (2003). This Directive is widely referred to in the literature. See for example, Contact Hamilton, *Community Plan*, *supra* note 459 at 5, which says “In January 2001, the child welfare agencies received a directive from the Ministry not to initiate any new Special Needs Agreements.”

⁸⁶² See *Ontario CFSA* s 30, Special Needs Agreements in former *Child and Family Services Act*, RSO 1990, c C.11

⁸⁶³ Residential respite and short breaks had been available to parents through s 30 of the *CFSA*, *supra* note 762, through individualized agreements.

⁸⁶⁴ The new statute, renamed as the *Child, Youth and Family Services Act* came into force April 30, 2018. It is not the subject of discussion in this thesis beyond saying that it does not provide the care that s 30 made discretionarily available who caregiving mothers who required it, at least on paper.

respite programs, which “assist” with or “enhance” what is primarily care provided by mothers at home, were put on offer through a tightly means-tested policy.⁸⁶⁵

Instead, children have had to be found to be in need of protection in order for state provision of disability-related care. Under ordinary circumstances, a child who is made a society or Crown ward, which consists of being court ordered into in the permanent legal care of the government, the reason is related to some named form of significant incapacity to parent their child. The incapacity has to be proven in court with evidence that satisfies a court that it is necessary to terminate the parent child relationship. Dedicated, high-functioning parents with intact parenting capacity who want to keep their children do not find their children made wards of the state under this provision, unless their child has a severe disability.⁸⁶⁶ Then they may find themselves consenting to temporary or permanent wardship in order to access needed complex care. By default, this has been an Ontario support policy.

Next, I describe an avenue of private support which I suggest has taken on increasing levels of importance as the state continues to abandon its role in support provisioning to caregiving mothers with disabled children.

The Family Law Arena

Although not technically a provincial support offering, I nevertheless include family law policy here. Provincial provisions for homecare and social benefits described above comprise public support to children with disabilities and their mothers. Family law, on the other hand, results in a private and privatized form of support to children primarily, but also to former partners, most often mothers. While the support itself is private, the structuring of family law (legislation, and procedures and practice) is

⁸⁶⁵ An example of a modest award through ACSO would be the afore alluded to award to appellant John Wood by the Director of the ACSO program in 2009 of \$25 a month plus a health benefits card (which he did not need as he had coverage through his employment). See OMCSS, *Statistical Report*, *supra* note 829. This amount was awarded after he internally appealed the denial of any support through the ministry. See *Wood v Ontario (Director of Children with Severe Disabilities)* (2009), Decision 0908-07140 (OSBT) [Wood]. The last time quanta of support for eligible children and parents was adjusted for inflation was in 1998 and it was at 5.4%. John Wood was disqualified for a larger amount of support by the Director of the ACSO program based on the decision that his income was too high. He sought support to defray the costs of air travel to Alberta for Grace, his severely disabled daughter’s heart surgery. The OSBT hearing officer held that pursuant to s 3(1) that household income was one factor to be considered by the Director but so too were other expenses, and that \$25 was not consistent with the purpose of the ACSO program. The ACSO program had what the Tribunal member described as a “self-imposed” guideline and noting it was not law, rather, it was discretionary. Moreover, she found that the situation warranted the use of discretion so that the flights could be paid for. The Tribunal member stated that in being bound by the law, the Director must consider all of the issues and determined that the Wood family ought to receive \$430 a month, the maximum amount under the program.

⁸⁶⁶ Child protection legislation is not something they would encounter. It is “against stated government policy; no parent should have to give up their children in order to secure residential placement for them.” Ontario Ombudsman, *Between a Rock and a Hard Place*, *supra* note 187 at para 157. Yet, as the Report states, the practice of Ontario has been to inform the Ombudsman in writing in regular six-month intervals that “we are studying the matter”, *ibid* at para 135.

public. However, with regard to the family law support itself being “private”, the state itself does not always deal with it as if it were actually private support in nature. This is because, as I discuss later, private support attracts public attention, and has been subject to clawbacks and scrutiny. Mothers who are seeking state support, or who have state supports already, may be required to interact with welfare officials about their non-public support. This is true whether the parties have privately ordered their support away from court, through mediation for example, or where the courts have ordered that support be paid. I shall return to this issue.

Family law is described on the Government of Canada Department of Justice website as a government justice service.⁸⁶⁷ The website provides a basis upon which to describe family law as, at least partially, public law, although in the setting of support for mothers with disabled children, it is a domain that aims to privatize support, paid primarily by fathers. There is information on this website for support-seeking payees, who are primarily mothers. This information is largely in respect of inter-jurisdictional support and support enforcement, which would require recourse to the courts. Notably, the onus is on mothers to get those processes underway in respect of potential and delinquent payors.

In Canada, there is divided jurisdiction when it comes to family law. The federal *Divorce Act* governs the granting of divorces, and ancillary matters of custody, access and support, including child, and spousal support. Each province and territory has its own family law legislation⁸⁶⁸ to deal with separation, custody and access, and child support.

Although there are Federal Child Support Guidelines (FCSG) in place for children whose parents are separating or divorcing, there is some variation in how they are calculated by individual provinces.⁸⁶⁹ This discrepancy is in keeping with the overall nature of support policy for mothers with disabled children in Canada, in that it is not dealt with identically across jurisdictions, or always in the same way in a given province. For example, the federal law, divorce support regime is not identical to provincial family law support regimes. This feature has been challenging where mothers of age of majority disabled children seek support through provincial legislation. The latter is not a straightforward support seeking

⁸⁶⁷ See Department of Justice Canada, “Inventory of Government-Based Family Justice Services”, online: <<http://www.justice.gc.ca/eng/fl-df/fjs-sjf/brows-fure.asp>>.

⁸⁶⁸ In Ontario, it is the *Family Law Act*, RSO 1990, c F3 [*Family Law Act*], in British Columbia is the *Family Law Act*, SBC 2011, in the Northwest Territories it is the *Family Law Act*, SNWT 1997, and so on.

⁸⁶⁹ For example, both the Federal and Ontario versions of the child support guidelines contain a provision that provide for a potentially higher calculation of child support for payors with incomes over \$150,000. See Section 4 of the Child Support Guidelines provides: Incomes over \$150,000: S. 4 Where the income of the spouse against whom a child support order is sought is over \$150,000, the amount of a child support order is (a) the amount determined under section 3; or (b) if the court considers that amount to be inappropriate, (i) in respect of the first \$150,000 of the spouse’s income, the amount set out in the applicable table for the number of children under the age of majority to whom the order relates; (ii) in respect of the balance of the spouse’s income, the amount that the court considers appropriate, having regard to the condition, means, needs and other circumstances of the children who are entitled to support and the financial ability of each spouse to contribute to the support of the children; and (iii) the amount, if any, determined under section 7. The SCC interpreted this provision in *Francis v Baker*, [1999] 3 SCR 250.

process, as it may be in the case of a minor disabled child, and is more often litigated with difficulty and expense.

The provisions under the *Divorce Act* are clear: a mother may bring a claim for disabled adult child support in the event that such a child is unable to support him or herself, provided the mother was at one time married to the payor.⁸⁷⁰ Under Ontario law, until July 2017,⁸⁷¹ unmarried mothers lacked the ability to bring the same claim as married or formerly married mothers do under federal divorce legislation. This has to do with the fact that regulation of family law falls within both federal and provincial jurisdiction. Ontario did not choose to provide the same adult disabled child support in its provincial statute.⁸⁷² There is also no accommodation in the family law legislation (provincial or federal) of the need of some severely disabled children to attend education programs part-time and also to receive adult child support in this endeavor.

On a separate but related point, although not a direct form of support, provinces do provide legal aid certificates to low-income or unemployed mothers who are seeking support through family law legislation, or who seek to obtain or retain custody of their children. However, legal aid in family law, is for low-income mothers, and many mothers self-represent when they would rather not.

In spite of its many constraints, which will become apparent in my examination of private support litigation, family law nevertheless plays an important supporting role in obtaining financial and tangible forms of support for mothers with severely disabled children, especially because rather than stepping up to provide them, the state has increasingly cut back supports.⁸⁷³ Family law support has been critiqued as

⁸⁷⁰ The Federal *Divorce Act*, RSC 1985, c 3 (2nd Supp), s 2 (1) provides:

“child of the marriage” means a child of two spouses or former spouses who, at the material time...

(b) is the age of majority or over and under their charge but unable, by reason of illness, disability or other cause, to withdraw from their charge or to obtain the necessities of life;

Where parties are unmarried, to provide a provincial example, the Ontario *Family Law Act*, s 31 (1)-(2), sets out:

(1) *Obligation of Parent to Support Child* – Every parent has an obligation to provide support for his or her unmarried child who is a minor or is enrolled in a full time program of education, to the extent that the parent is capable of doing so.

(2) *Idem* – the obligation under subsection (1) does not extend to a child who is sixteen years of age or older and has withdrawn from parental control.

⁸⁷¹ *Coates v Watson*, 2017 ONCJ 454

⁸⁷² Mary Jane Mossman, Natasha Bakht, Vanessa Gruben and Karen Pearlston. *Families and The Law*. Cases and Commentary. 2nd ed. (Concord: Captus Press, Inc. 2015) at 47.

⁸⁷³ However, case law shows that family law frequently intersects with “public law”, and to a greater extent for adult disabled children. One can see why Frances Olsen includes in her definition, *the relations of those outside the family to those inside the family*, “The Politics of Family Law” (1984) 2:1 Law & Inequality 1 [Olsen, “Politics”]. A recent example of this is the family law case, *Senos v Karcz*, 2014 ONCA 459, 120 OR (3d) 321, which addressed OSDP income support to an adult child in a very expensive and protracted child support dispute, involving a father who could afford to pay for this extensive litigation and assumedly a litigator who acted for the mother at a low fee or no fee. Today, based on *Senos*, child support payments are exempt if paid pursuant to a court order and are applied to disability-related costs, services, education, or training and approved by the Director. This approach does not address care or services provided by the caregiving mother (in this case of a “child” (who was over 18) who lived with his mother and who had a very serious mental illness).

a form of support set up in the service of the state to ensure the state pays less than it would otherwise.⁸⁷⁴ Feminist legal scholar Frances Olsen defines family law more expansively as referring to legislation, regulations and court decisions involving: family formulation; rights and duties of family members to one another; the relations of those outside the family to those inside the family; and, the dissolution of the family.

A Discussion Concerning Policy Approaches

As a mother accessing government disability supports in Ontario, I did not give much thought to the ways in which supports were formulated, or described. Years later, I am aware that policy critics claim that the government's aim is to ensure that state support remains obscure and uncertain.⁸⁷⁵ Now, after several years of examining support issues, I continue to come across mention of benefits I have not previously encountered.⁸⁷⁶

Features of elusiveness, uncertainty, and obscurity in the availability of state supports relate to societal expectations placed on mothers to provide care. If mothers are responsible, then what the state offers is treated as though it is of secondary importance. Such expectations were expressed federally in 2000 in the *National Children's Agenda: Developing a Shared Vision*.⁸⁷⁷ Despite the title of this report, shared visions mean different things to different groups and moreover, such visions cease to be those of many mothers who seek support in the setting of severe disability, who come to realize that the supports they envision and need differ from those being offered.

As noted above, public supports for disabled children and their mothers under provincial authority are decentralized. Although the federal government has been involved in child disability support, initiatives have been limited. Notable are the inclusion of disability under s 15 of the *Charter*, and the aforementioned *National Children's Agenda: Developing a Shared Vision* document.⁸⁷⁸ As well,

⁸⁷⁴ See discussions in Anna Stepien-Sporek & Margaret Rysnar, "Child Support for Adult Children" (2011-2012) 30 *Quinnipiac L Rev* 359 at 364. Conversely, these authors state federal government involvement in US child support enforcement ensures tax payers are not carrying costs for otherwise unsupported children.

⁸⁷⁵ Canadian social benefit policy expert, Michael Prince, discusses this in "'Soft Craft, Hard Choices', Altered Context: Reflections on 25 Years of Policy Advice in Canada" in Laurent Dobuzinkis, Michael Howlett & David Laycock eds, *Policy Analysis in Canada: The State of the Art* (Toronto: University of Toronto Press, 2007) 163. It is often assumed that policy has a legislative base, when in fact social policy is simply what government decides to do, or not do. The *Nieberg* decision which I address in Chapter Six refers to "additional money", and "This additional fund", unnamed which I had not seen reference to in the policy literature. It is an example of what I refer to as an obscure form of funding. One that only mother's in know would be able to apply for. *Nieberg*, *supra* note 785 at para 6.

⁸⁷⁶ A fund was made available by the MCYS in 2001 and accessed by the litigating parents in *Nieberg*, *supra* note 785, and is referred to in that decision. That unnamed fund was the fund in respect of which that application for judicial review was brought, and not in respect of funding under the *CFSA* since that *Act* no longer provided funding or care. However, the *Act* was referred to by the court, as governing the way this fund was dealt with by the MCYS.

⁸⁷⁷ *Developmental Services Act*, RSO 1990, c D.11, as repealed by *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, 2008, SO 2008, c 14, ss 63-64.

⁸⁷⁸ Noted by McKeen to be one of many such initiatives in Canadian policy history. McKeen, *supra* note 491 at 153.

there are Senate committee hearings, federal income tax initiatives,⁸⁷⁹ periodic reports to the United Nations respecting Canada's compliance with international law, Public Health Agency initiatives,⁸⁸⁰ the 1993 Federal/Provincial/Territorial Review of Services Affecting Canadians with Disabilities, the 1996 Federal Task Force on Disability Issues, and the 2002 Commission on the Future of Health Care in Canada.

However, of these last three initiatives, none had disabled children/childhood disability as their major focus.⁸⁸¹ The *National Children's Agenda: Developing a Shared Vision* discussion paper, published in 2000, has been described as geared towards income support for families with modest means⁸⁸² and touted the formulation of cross-Canada comprehensive policy for children. One of its aims was to promote inter-provincial communication about successful practices concerning policy for children. The shared vision was predicated on "the critical and primary role that parents, families and communities" play in children's lives.⁸⁸³ Silent in this aim are reference to mothers specifically, whose care labour is subsumed under the gender-neutral term "parents". As noted previously, in its initial iteration, this document was also silent on the issue of disabled children.⁸⁸⁴ These silences are together worthy of note, for they translate into mothers providing disability care without recognition.

In support of my claim, in 2007, there were Senate hearings in respect of Canada's compliance with the United Nations *Convention on the Rights of the Child (CRC)*. The *CRC* has relevance to mothers with disabled children. The primary aim of the Senate hearings was an inquiry into the extent to which the *CRC* has been implemented in Canada, and whether it is used as a tool to address problems children experience. Another stated aim was to examine the role of parliament vis-à-vis the *CRC* framework. These hearings were published in the Report of the Standing Senate Committee on Human Rights, *Children: The Silenced Citizens*.⁸⁸⁵ In this 283-page document, just seven pages were devoted specifically

⁸⁷⁹ Examples would be the child tax benefit currently in place and the child disability tax credit and *Income Tax Act*, RSC 1985, c 1, approved tax- deductible disability related items.

⁸⁸⁰ Federal legislation might also be described as a Federal initiative, for example, the inclusion of disability as a protected ground in the *Canadian Human Rights Act*, RSC 1985 c H-6. There is also the ratification of the *CRPD*, *supra* note ##, and the UN *Convention on the Rights of the Child*, 2 September 1990, 1577 UNTS 3 [*CRC*], and other international aspirational initiatives that lend weight to policy and law.

⁸⁸¹ See Roher, *Federal Transfer Options*, *supra* note 793 at 2. Health Canada has also addressed issues concerning homecare, but again the major focus has not been on children with severe disabilities.

⁸⁸² See McKeen, *supra* note 491 at 153.

⁸⁸³ Government of Newfoundland and Labrador, News Release, "Measuring Child Wellbeing and Monitoring Progress" (10 May Government of Newfoundland and Labrador, 1999) online: Government of Newfoundland and Labrador <<http://www.releases.gov.nl.ca/releases/1999/health/0510n04.htm>>. This work was released along side the *National Children's Agenda* *supra* note 476.

⁸⁸⁴ See Prince, "Governance", *supra* note 437 at 394, 402.

⁸⁸⁵ [Senate Report] *supra* note 757. A relevant aspect of the report is that it points out that provincial provisions pertaining to specialized health services for children are usually qualified by the words "subject to available resources" and rely upon parents showing hardship to access supports.

to disabled children.⁸⁸⁶ However disability is referenced in the context of very important issues in a few other sections of the Report. For example, it states that 75-80% of Saskatchewan youth in detention have disabilities.⁸⁸⁷ The report did underscore that there is a great deal of work to be done for marginalized children from different groups, but disabled children were not a focus. Thus, as with *The National Children's Agenda*, disabled children were marginalized in this document as well.⁸⁸⁸

The Senate Report points to inconsistent access to programs between provinces and between regions within a given province.⁸⁸⁹ Recommendation 15 called for the federal, provincial and territorial governments of Canada “to implement an improved process to improve services to special needs children by July 2008.”⁸⁹⁰ This is a similar issue to the one governments addressed in the *National Children's Agenda* several years earlier.⁸⁹¹ Importantly, this Report describes the policy situation for disabled children in Canada as *a crisis* requiring consultation “with advocacy groups, service providers, health professionals and special needs children to resolve.”⁸⁹² However, mothers are not targeted or even commented on as a group in this section of the Report.⁸⁹³ This is ironic, given that the Report's title refers to silenced citizens. One way to silence the voicing of disabled children's needs is to marginalize their mothers.

There is reference in the Senate Report to the eagerness of the Federal Government of Canada to ratify and implement the United Nations *Convention on the Rights of Persons with Disabilities (CRPD)*. While Canada ratified the CRPD in 2010, it remains far from implementation.⁸⁹⁴ In any event, the *CRC* has long included provisions in respect of support and rights for disabled children and their caregivers.⁸⁹⁵

⁸⁸⁶ The focus was on autism and fetal alcohol syndrome disorder.

⁸⁸⁷ [Senate Reprt] *supra* note 757 at 91.

⁸⁸⁸ In his submissions to the Senate, Lawyer and disability advocate Yude Henteleff, is quoted as referring to our system of childhood disability supports as “economic rationalization for discrimination.” *Ibid* at 158.

⁸⁸⁹ *Ibid* at 159.

⁸⁹⁰ *Ibid* at 164.

⁸⁹¹ Given what is stated in this report, that there is inconsistent access to programs between provinces and between regions within a given province, one can envision certain kinds of extra-provincial problems arising for mothers of disabled children in need of support continuity and support security. For example, if an Ontario mother wishes to move to Vancouver for work, her child disability supports do not follow her. If an Ontario parent can access a rare paediatric organ surgery available only in Calgary, she may find Ontario will not agree to cover travel and other costs associated with seeing the child's surgery through. See *Wood, supra* note 865. A child with severe autism may be better in a well-off province like Alberta, than in say Nova Scotia or British Columbia. This is the reason Jeremy Bostick was taken to Alberta, away from Ontario where his mother lived.

⁸⁹² Senate Report, *Children: The Silenced Citizens*, *supra* note 757 at 164.

⁸⁹³ While the section of poverty makes comments about the UN *Convention on the Elimination of All Forms of Discrimination Against Women*, 18 December 1979, 1249 UNTS 13 [CEDAW], and single mothers in poverty, the report does not connect the dots between poverty, single motherhood and severe disability in children.

⁸⁹⁴ See Chantal Collins, “Canada and the Convention on the Rights of Persons with Disabilities” online: (2012) 89 Parliament of Canada Hill Notes <<http://www.parl.gc.ca/Content/LOP/ResearchPublications/2012-89-e.htm>>.

⁸⁹⁵ Where disabled children are concerned, the *CRC* was criticized as not being within the social model, unlike the *CRPD*, I point out that the *CRPD* however is not within a maternal model, also problematic given who provides care to children.

Article 23 provides that states are to provide special care to and available resources to disabled children and the person responsible for their care, for example. It also provides that states are to have regard to income of parents in allocating supports in diverse areas.⁸⁹⁶ The section in the Senate Report on *Child Protection Issues* noted legal concerns that are particularly relevant to severely disabled children who are before the courts.⁸⁹⁷ In the general section on “Children’s Health”, under “Special Needs”, the Senate Standing Committee document *Pay Now or Pay Later: Autism Families in Crisis* is mentioned.⁸⁹⁸ The latter title demonstrates government interest in what autism costs society, and is derived from a discourse other than that of disability rights.⁸⁹⁹ Closer attention should have been paid to Recommendation 15 noted above, as calling for the federal, provincial and territorial governments “to implement an improved process to improve services to special needs children by July 2008”⁹⁰⁰, which is ten years ago now. It is challenging to understand what has occurred to prevent this. However, whether to even collect data on disabled children has been politicized in Canada. Prior to 2006, the Participation, Activity Limitation Survey (PALS) portion of census data collection for children was a federal government initiative in the area of childhood disability. Reflecting the already low interest of the federal government in research-based policy, the census was terminated by the Conservative government of Stephen Harper. However, it has been reinstated by the newly-elected Liberal government.

This situation highlights the vulnerability of disabled children and their mothers to political swings. Not having responsibility under the Constitution for the support of mothers with disabled children, the federal government is largely uninvolved and does not engage in oversight or even social policy commentary.⁹⁰¹ The Federal government has sought to deepen its low level of involvement in the past. For example, the Conservative government of Stephen Harper defended its decision not to fund health care for all refugee children. This meant certain refugee children with medical disabilities would be without medical care.⁹⁰²

⁸⁹⁶ CRC *supra* at note 880.

⁸⁹⁷ Issues such as the right to be heard (Article 12) and the right not to be separated from one’s parents (Article 9) and the application of the best interest of the child standard were among those issues canvassed as concerns. Article 9 refers to the requirement of judicial review by competent authorities, in accordance with applicable law and best interests. Note was made in the Senate Report of the fact that in some jurisdictions children were not parties, at 101. This issue is clearly a concern in cases such as *J.M.S. supra* note 15 and discussed below.

⁸⁹⁸ Senate, Standing Committee for Social Affairs, Science and Technology, *Pay Now or Pay Later: Autism Families in Crisis* (March 2007) (Chair: Art Eggleton) online:
<<http://www.parl.gc.ca/Content/SEN/Committee/391/soci/rep/repfinmar07-e.htm>> [Senate Report, *Pay Now*].

⁸⁹⁹ The erstwhile Federal Conservative Government of Canada, 2006-2015, chose in this arena not to include the rights of autistic children. Policy advisor, Cam Crawford has told me that a new PALS is in the field as of writing.

⁹⁰⁰ Senate Report *supra* note 757 at XXII

⁹⁰¹ This is with the exception of specific special initiatives, like the Health Canada’s 1999 *National Children’s Agenda*, *supra* note 476 or the 2007 Senate Report, *Children: The Silenced Citizens*, *supra* note 757, looking into Canada’s international obligations and so on in respect of child rights and other such endeavors.

⁹⁰² See *Canadian Doctors for Refugee Care, v Canada (AG)* 2014 FC 651 [*Doctors for Refugee Care*].

Federal presence is felt by the provinces, but not in a public support capacity. An example of how the federal government sees its role is evident in the statement made by a spokesperson directly after B.C.'s Angie Robinson killed her severely disabled son Robert, and herself, after being unable to access needed state care. The disembodied statement made to media by the federal government was that "[t]he Public Health Agency of Canada is working with its partners in the provinces and territories to develop the infrastructure necessary for a national autism spectrum disorder surveillance system."⁹⁰³ What could they say? Not only is such support to caregiving mothers not within federal jurisdiction, autism is not something the federal government is interested in supporting.

In this chapter, I have shown ways in which state representations of care are manifested through provincial choices regarding relevant law and policy. The information I have provided demonstrates that support policy is inadequate across numerous parameters. Policy has been shown to be balkanized, disorganized, weak, confusing and elusive. Moreover, there are barriers to access that stand in the way of the few supports that are available. Aspects of disability support legislation, both public and private, have likewise been identified as problematic and in need of reform. It should be no surprise that support-seeking mothers with disabled children are engaged in litigation in respect of laws and policies with these flaws.

In the next chapter, I continue with a discussion of a major flaw, that of weak support law and policy accountability and flowing from this discussion, I move into an examination of mothers and their disabled children's disputes with the state.

⁹⁰³ Erika Tucker, "Mother-Son Murder Suicide Highlights Lack of Autism Funding in Canada", *Global News* (25 April 2014) online: Global News, <<http://globalnews.ca/news/1292113/mother-son-murder-suicide-highlights-lack-of-autism-funding-in-canada/>>.

CHAPTER SIX: Disputes With The State

Introduction

In this chapter, I first address the problem of weak accountability, a term I explain below, to caregiving mothers in public support law and policy. This discussion is important because it sets the stage for my examination of mothers' political activities and public litigation, much of which is situated in social benefit law.

I also provide examples of lawsuits brought by mothers with disabled children that uncover the social, legal, and political myths that undergird the system of public support. I argue that in exposing and contesting these myths, which exist to maintain a societal vision of disability care and women's role in relation to it, some caregiving mothers' activities indicate their acquiring a critical consciousness about their political circumstances.⁹⁰⁴

According to Freire, myths are "lies" that have been "knowingly imposed" on oppressed people without regard to the circumstances of their reality.⁹⁰⁵ Myths that support-seeking mothers encounter, or live with, and which prevent many from acquiring recognition in the political economic order, fall under the microscope of legal analysis in decisions that demolish mothers' claims.⁹⁰⁶

I start from the position that it is through their own praxis involving what they have learned while caring, that some litigating mothers appear to have come to understand that the Canadian state provides only meagre support in limited settings, based *not* on maternal-disabled child realities, but based on state interests instead. The case law examined reveals that mothers with disabled children have difficulty realizing their rights to support in public law for many reasons. These include deferential courts, the exercise of discretion granted in legislative provisions, and problems with the law itself. These issues co-exist and interact with myths that are either embedded in law itself, or are brought into play in legal proceedings.

⁹⁰⁴ Given that the care involved is often medical in nature (rehabilitation therapy, speech therapy, tubal feeding, monitoring of respirators, tracheotomy, bowel, wound and adult menstrual care and toileting, etc.), it is political in that in Canada we have construed some but not all medical care as a state obligation. Hospital and physician care is to be covered by provincial public health insurance.

⁹⁰⁵ Such myths are internalized by mothers, as Freire posits in *Pedagogy*, *supra* note 131. For example, mothers may believe the ceiling of their quanta of entitlement to support is the guideline amount in support policy provisions. Never mind that they may be unaware bureaucrats are meant to exceed recommended guidelines in cases that warrant such a measure, mothers may also be unaware that the process contains and curtails the development of a wider more comprehensive entitlements to support. Development of maternal imaginaries respecting their entitlement to support that differ from the dominant social imaginary they must operate within, are thus kept in abeyance.

⁹⁰⁶ In keeping with the methodologies described by Elizabeth Bartlett, *supra* note 39, and A.W. Phinney III, *supra* note 53, and within the conceptual frameworks of standpoint theory and critical consciousness as outlined in Chapter Two.

After addressing weak state accountability, and the implications of it, I discuss mothers' efforts to contest the myths surrounding disability care and support of it, through litigation. I begin with the central myth of maternal autonomy, and follow this with an analysis of the myths of abandonment and protection. From this, I turn to the myth of extraordinary mothering, which dominates private and public law. I go on to address political myths, the myth of equality for caregiving mothers generally, and then I zero in on the myth of accessible healthcare.

My analysis of these myths along with mothers' efforts to reveal the truth in the face of them, serves to illustrate how public law corrals mothers' claims for support in the setting of childhood disability, rather than facilitating them. The overarching difficulty however, is that of mothers' inability to hold the state accountable for their ongoing support, the very thing to which, I argue, they have a right.

The Main Complaint: Lack of Accountability

The disputes that caregiving mothers most often have with government concern government benefits in the form of services, funding, and supports that are made available on a discretionary basis. An example would be the allocation of home nursing care hours for a severely disabled child requiring 24 hour a day enhanced 'respite' care. Before providing examples of lack of government accountability seen in the lives of caregiving mothers in need of support, I first address what I mean by the term "accountability". In fact, I mean two things. I use the term in the sense that administrative and *Charter* rights law scholar Lorne Sossin does in one of his articles in which he calls for government accountability in legislation, regulation, rules, guidelines, and established government practices which would be reflected in "meaningful standards for public scrutiny of Ministerial discretion."⁹⁰⁷ This would include review of decisions involving discretion as to their constitutionality, as Sossin discusses. Not only are there not meaningful standards in many areas of discretionary supports to mothers, there are also occasions where there are no standards at all. For example, as seen in Ontario homecare case I discuss in this chapter involving a mother with a child with Progeria receiving too few pediatric nursing hours from a CCAC, which left her scrambling and desperate and with *no recourse*.⁹⁰⁸ That is the legal meaning of accountability that I have in mind. However, I also have in mind the notion that certain groups of people, which would include less affluent mothers with severely disabled children who rely on social benefits, are treated as less worthy of reasons, rights to appeal, and so on than are other sectors of the population. This too is a form of lack of accountability, a disability and gendered one.

A consideration of accountability involves analysis of both the political forces that shape relevant support programs, as well as analysis of the nature of programs themselves. It also involves discussion of

⁹⁰⁷ Lorne Sossin, "Discretion Unbound: Reconciling the Charter and Soft Law" (2002) 45 Can Public Administration 465 at 478 [Sossin, "Discretion Unbound"].

⁹⁰⁸ *LS, supra* note 164.

the bureaucratic culture in which such support is denied or awarded. I have already introduced a sketch of the kinds of provincial supports on offer. In service of a politically conservative approach to state supports for those in need of them, bureaucratic practices that arose after the withdrawal of much of the welfare state's supports in the 1990's involve intensive gatekeeping, and zealous means-testing, functionally designed to provide support to those who are of low or modest income. The bureaucratization of policy delivery, moreover, involves bureaucratic norms that favour high levels of discretion being wielded by protectionist and officious bureaucratic decision makers, many of whom lack expertise in childhood disability or caregiving. On the rare occasion when they are knowledgeable, that expertise is not employed to the benefit of mothers in need of support, because systemic barriers and the policy culture stand in the way.

To illustrate this concretely, former Minister of Children and Youth Services, the Honourable Marie Bountrogianni, with whom the Ombudsman communicated concerning Ontario's practice of requiring parents to relinquish custody of their children before disability care would be provided, had experience working with families. She has a doctorate in psychology, which she put to use as a child psychologist for the Toronto District Board of Education, and also as the chief psychologist at the Hamilton Board of Education. Her Ministry's response to Mr. Marin, discussed above, in which government reassured the Ombudsman that issues he raised were important and had been taken into consideration,⁹⁰⁹ speaks to the issue of weak accountability. Then Minister Bountrogianni stated to the media, "[t]he children's aid societies are there for protection... They are not there to take parental rights away from parents of severely disabled children."⁹¹⁰ In this same interview, she stated that she had given a re-directive to child welfare not to require the relinquishment of custody. However, one advocate is quoted in this same article as stating that "Bountrogianni's directive is toothless because it has been issued before by this government and the previous government."⁹¹¹ Media reports indicate that there was unevenness across regions and lack of coherence between what was reported in the media, by the Ombudsman, and by those agencies governed by her Ministry. Bountrogianni stated that the issue was "a real issue" in southern Ontario" but that it was not an issue in her riding of Hamilton.⁹¹²

Note that in this same time frame, the regional offices of the MCSS and MCYS asked CONTACT Hamilton to facilitate development of a plan regarding the ongoing unmet needs of children and youth

⁹⁰⁹ See discussion in Chapter Three.

⁹¹⁰ Pearson, "Parents of Disabled Kids", *supra* note 626. See also Craig Pearson, "Ailing Kids' Parents doubt CAS directive", *The Windsor Star* (11 May 2005) A2; and Craig Pearson, "Custodial Rights will be restored, Minister says", *The Windsor Star* (27 May 2005) A2 [Pearson, "Custodial Rights"].

⁹¹¹ Pearson, *supra* 910 "Ailing Kids" *The Windsor Star* (11 May 2005) A2.

⁹¹² *Ibid.*

with complex developmental or mental health needs.⁹¹³ While the state's supports of children (and families) targeted in the CONTACT Report are amongst those included in my dissertation, they represent only a segment of those under discussion. Children and youth with complex mental health disabilities (addiction suicidal ideation or attempts, criminalized youth on the one hand, and those with developmental disabilities (autism spectrum primarily) on the other, do not represent the full spectrum of severely disabled children. They do not share identical care needs with children with severe medical complexity or children with medical complexity and also co-morbid mental health and developmental disabilities. So in spite of this effort, children in need of support, and their mothers would be left out of policy consideration. Next, I provide other examples of weak state accountability in the area of support to show that mothers are without recourse to ameliorate their circumstances, which lends support to my later argument that they should have special treatment in law.

Prince has stated that “charting the public sector reveals a complex, dense, and often overlapping policy sphere” with “weak accountability mechanisms.”⁹¹⁴ Weak accountability poses a problem not only provincially. The federal government has a direct role to play in some policy domains, and an example of that is the income tax regime. The federal government also indirectly plays a role through the federal funding of areas of provincial jurisdiction. A range of necessary childhood disability expenses are not deemed legitimate under the *Income Tax Act* and thus, are not permitted as tax deductions. This is so even though the Canada Revenue Agency (CRA) has long been alerted to the high costs of disability care.

In *Henschel v The Queen*⁹¹⁵ an appellant father, with the mother acting as his agent, claimed as deductions the following goods and services: caregiver training, therapy, travel expenses for medical treatment, equipment, mattresses and mattress covers and other items. The federal government rejected these expense claims as not included as deductible under the *Act*. Mr. Justice Bédard opined that the Appellant's case had merit, but held that he should seek legislative change, not judicial review. Justice Bedard added that it was beyond the power of the judiciary to award such deductions. The court further opined that “one can only hope that Parliament will take into consideration the astronomic economic burden borne by parents of autistic children and that the *Act* will ultimately be amended to broaden the definition of ‘medical expenses.’”⁹¹⁶

The Federal government does provide a child disability benefit (CDB) in the amount of up to \$2,730 per year for families caring for a child under age 18 with a severe and prolonged impairment in

⁹¹³ CONTACT Hamilton. Working Group Report: Systems and Supports For Youth and Children With Complex Care Needs”. September 2004-May 2005, at 1.

⁹¹⁴ Prince, “Governance”, *supra* note 437 at 390.

⁹¹⁵ *Henschel v The Queen*, 2010 TCC 344 [*Henschel*].

⁹¹⁶ Mr. Justice Bédard in *Henschel*, *supra* note 915 at para 14. The father was the named plaintiff; the mother gave evidence in the proceeding. The mother argued that supplies for the children's therapy should be covered under paragraph 118.2(2)(1.9) since therapy required these items. The court did not agree.

physical or mental functions. The child's condition must be certified by a physician on the Disability Tax Credit Certificate form and the Canada Revenue Agency (CRA) must approve the form. Of note, the amount of the benefit is adjusted for those with net income over \$65,000.⁹¹⁷ Although the aim of the credit is to support those with severely disabled children, it would barely cover the annual cost of one full day of respite per week.

Henschel points to the failure to include the manifold and actual costs of care to disabled children under the income tax scheme in Canada. This omission with regard to deductions continues to pose barriers to support through the tax regime. This, I argue, is part of the larger state vision of care of disabled children as private, rather than public, and comprising social, rather than medical care. This issue is appropriately seen as the under-inclusiveness of disability in support law, a feature which makes it challenging for mothers to realize their rights to support, short of convincing CRA to make an exception in their case, or hoping that a judge will venture outside the expected constraints of his or her role, which ought not be their burden to shoulder.⁹¹⁸

Henschel reveals that at the federal level, government is not sensitive enough to the undue burdens of the cost of caring for severely disabled children. Allowing the deduction of a few such expenses against income tax, along with a meagre monthly benefit offers only partial support to strapped caregiving parents, and reflects weak government accountability to parents paying the costs of such care. Above all, it reveals that private care provision is not rewarded with fair taxation.

Weak accountability may also be seen to occur where mothers' circumstances are not considered. This may take place in seemingly unlikely areas. In *A.B. v City of Toronto* two poor single mothers and their children, one of whom had autism, brought an action against the City of Toronto with respect to a strike, during which city services, including those for special needs children, were cancelled. The mothers alleged the section of the *Labour Relations Act* permitting strikes by indoor employees infringed their rights under s 7 of the *Charter* in not providing alternative placements for their children.⁹¹⁹ The situation was particularly difficult for the mother with the child with autism.⁹²⁰ She alleged the strike was having a

⁹¹⁷ Government of Canada. Child Disability Benefit. Online< <https://www.canada.ca/en/revenue-agency/services/child-family-benefits/child-disability-benefit.html>>.

⁹¹⁸ While individual support seeking mothers may hope for activist judges, even if all of them were so, it is not an answer to the many systemic problems of support. The issue of whether courts can effect social change on their own, was the subject of a book by Gerald N. Rosenberg, *The Hollow Hope. Can Courts Bring About Social Change?* 2d ed (Chicago: The University of Chicago Press, 2008).

⁹¹⁹ Jeffrey Wilson who acted for the claimants, stated at the time it was brought that it may not get to first base and may be the first of its kind. See Josh Wingrove, "Moms Sue Over Strike", *The Globe and Mail* (17 July 2009) online: <<http://www.theglobeandmail.com/news/national/moms-sue-over-strike/article4289174/>>.

⁹²⁰ *A.B.*, *supra* note 52 at para 49, states that in preparing the factum in this matter, a search was conducted of debates and proceedings in the Ontario Legislative Assembly and its Committees from 1984 to the time of the case. This was done to discern whether such had made any reference to the interests of children in the law in the *Labour Relations Act*, SO 1995, c 1.

“severe impact upon the welfare of our autistic children.”⁹²¹ The impugned legislation in *A.B.*, regarding a city wide strike by Toronto municipal workers, failed to consider mothers’ needs to access city services which impacts mothers with disabled children more than it did the average person.⁹²² This can also be seen simply as a failure to accommodate caregiving mothers. Suitable alternative programming ought to have been made available.

Weak accountability is likewise reflected in other legal disputes, such as those regarding the obligation of the provincial government to fund programs for severely disabled children. Such disputes may include the feature of lack of inter-governmental agreement. *G.E. v Alberta (Child Welfare Appeal Panel)* is a case in which a parent of two autistic children sought funding for services from the Alberta child welfare system and was denied it by the Director.⁹²³ G.E. appealed the refusal, but the Appeal Panel dismissed the appeal, stating it lacked jurisdiction to adjudicate the dispute and referring to another statute as governing the concern. G.E. subsequently brought a claim in the Court of Queen’s Bench. The court framed the issue as whether the sought-after funding was properly within the jurisdiction of the Alberta child welfare legislation. Determining that it was, Justice Rowbotham commented that ultimately, this case involved a dispute between two Alberta governmental departments as to which one ought to bear the cost of the “the provision of services to handicapped children.”⁹²⁴ If it is possible for different branches of government to refuse carriage of childhood disability files, where does that leave mothers? It leaves them stuck in the middle of a dispute that is not their own, without needed support. In his ruling, Judge Rowbotham referenced another case in which governmental departments “engaged in a war”⁹²⁵ respecting their budgets and obligations.⁹²⁶ The situation she alluded to was when, during the early days of the *Auton* litigation, the British Columbia government strategically moved its disability provisioning from one ministry to another in an effort to escape incurring a possible finding of a state obligation to fund services for some autistic children.

⁹²¹ *A.B.*, *supra* note 52 at para 21.

⁹²² *Ibid.* Where government does not want to remedy the situation *systemically*, it is in their interest to resolve these disputes *individually*. I suggest the cases that do get litigated are few in relation to number and variety of disputes between mothers and government. An extensive search did not result in my finding the outcome of this case.

⁹²³ *G.E. v Alberta (Child Welfare Appeal Panel)*, 2003 ABQB 846 [*G.E.*].

⁹²⁴ *Ibid.*, at para 1. In *Alberta, C.R.*, *supra* note ##, held that “Lovaas-type programs” constituted a service for handicapped children within the meaning of the province’s *Child Welfare Act* and ordered the director of child welfare services to fund 90 per cent of the therapy’s cost.

⁹²⁵ *G.E.*, *supra* note 923 at para 1.

⁹²⁶ Although beyond scope, I note that this is an issue federally as well, where severely disabled children in need of care and funding are concerned. Jordan’s Principle sought to address this. There are several excellent analyses of this issue. See e.g. Anne Blumenthal & Vandna Sinha, “No Jordan’s Principle Cases in Canada? A Review of the Administrative Response to Jordan’s Principle”, online: (2015) 6:1 Intl Indigenous Policy J <<http://ir.lib.uwo.ca/iipj/vol6/iss1/6>>.

The message is that no one wants to pay for disability care, not the child welfare system, and not Ministries of Health.⁹²⁷ Governments cannot (and will not) agree even among and within themselves as to whose obligation it is to support disabled children. As a result, the political landscape around childhood disability support is a contested one, with mothers being caught in an environment inhospitable to their claims.⁹²⁸

Weak accountability arises in other ways. Decisions may be made by bureaucrats with insufficient understanding of levels of support required.⁹²⁹ For example, a problem faced by support applicants is that the exercise of discretion by bureaucrats may result in mothers with similar circumstances receiving dramatically different levels of support. Further, some decision-makers may fail to use their discretion to make awards of support where warranted that do not accord with the schedules ordinarily followed by decision makers in their determinations.⁹³⁰

Decisional unevenness arising out of uninformed bureaucratic discretion results in haphazardly offered disability support. Pottie and Sossin state that the institutional culture, as well as the political environment in which decision makers operate, comprise another source of unevenness pertaining to discretionary decision making concerning social benefits.⁹³¹ They argue that there has been an under-examination of the administrative procedures and structures that support the making of the administrative decisions themselves.⁹³² Such processes are not neutral, but rather are embedded in a set of values

⁹²⁷ A situation that became politicized as a First Nations disabled child welfare funding issue. See Noni Macdonald & Amir Attaran, "Jordan's Principle, Governments' Paralysis" (2007) 177:4 Can Medical Assoc J 321.

⁹²⁸ The court in *G.E. supra* note 923 at para 14, opined ultimately that "The *Child Welfare Act* provides a scheme for the provision of a funding agreement (s.106), an appeal of the Director's decision to the Appeal Panel (s.120), and an appeal of that decision to the court (s.117). The Director must be given the opportunity to negotiate the funding agreement, assess the request and determine the amount of funding necessary and available. Until the Director has had that opportunity, there is no decision to appeal or review by the Appeal Panel or the court."

⁹²⁹ See *Self-Represented v ODSP*, 2013 OSBT 51 [*Self-Represented*]. In this case, the Director of the ODSP-Program sent a letter to the mother of two boys aged twelve and eighteen with profound autism to state that her benefits under the ACSD Program had been cancelled because her income exceeded the program eligibility cap in the support program Guideline. The mother requested an internal review, which confirmed the Director's decision to cancel the benefits. The mother raised the issue that the program decision was based on gross rather than net income and that the cap had not been changed in keeping with inflation for years. She submitted the process used by the Director to arrive at an amount of support was flawed. This shows another mother challenging government findings and their methods. She claimed the Director used a base income amount for the first child on ACSD benefits, and then allocated an income incremental amount for each additional child; rather than assessing the second child's specific disability requirements. This mother showed she had extraordinary expenses associated with care for her sons. The question arose on what basis the method of calculation for a mother caring for more than one severely disabled child was made. The Tribunal noted the mother "had her own health challenges", *ibid* at para 23, and held that "each child's severe disability needs/requirements should be assessed on their own merits and requirements depending on that child's specific disability since each child's needs are unique to each child", *ibid* at para 24.

⁹³⁰ There are many examples of this problem arising in matters before the social benefit tribunal. i.e Tali Lalkin's case discussed below in this chapter.

⁹³¹ Pottie & Sossin, *supra* note 498 at 164.

⁹³² *Ibid* at 161.

inimical to generous awards of support.⁹³³ Important to my project is the fact that it is clear from decided cases that bureaucratic decisions are based on a combination of assumptions about the role of mothers and weak understandings of the real-life needs of severely disabled children. This is compounded by conservative fiscal policy, which seeks to spend less. This combination can be risky (and has been deadly) for caregiving mothers in Canada and elsewhere.

Bureaucrats making decisions about support need to understand the nature of care burdens that prompt mothers to apply for benefits in the first place. And once they acquire that knowledge, they need to have the clear authority to deploy adequate resources. In order to ensure this, a different approach needs to be taken. Such an approach would presuppose the political will to put into place robust, multi-faceted oversight of all support programming. Presently, across Canada, (and as Jane Raca noted regarding such policy in Great Britain), each policy domain functions like its own little fiefdom⁹³⁴ and political will appears to be either missing or unable to express itself.

The policy fiefdoms described often appear to be in the service of the state and not in the service of mothers and their disabled children. For example, when a decision is made in respect of support, it is not a simple matter to have it reviewed. Nor is it a speedy or pleasant process. First, where disability benefits are concerned, there may be an internal ministry review. If that is not satisfactory, then there is an appeal to a provincial tribunal, and from there, to a provincial court. Judges may be unfamiliar with little-known childhood disability policy regulations, directives, policy manuals or other facets of disability support policy.⁹³⁵ Moreover, judges have concerns that policy is a political matter and not a judicial one, and that reviewing it may be beyond their court's jurisdiction. More so than other benefits, support for disabled children is often perceived as a private matter by many in the legal profession, and the act of considering it appears by some judges a task charged with adjudicating public law disputes. In addition, judges often have no line of cases on point to refer to when dealing with contested decisions and may feel uncertain as to the correct course of action.⁹³⁶ That said, in cases where the conduct of government veers far from what is required for administrative fairness, courts seem to have no difficulty quashing or sending decisions back to the originating ministerial authority on procedural grounds.⁹³⁷ One must note, however, that it is in no way easy to get to court. That is something that requires knowledge, energy, and

⁹³³ Lorne Sossin & Charles W Smith, "Hard Choices and Soft Law: Ethical Codes, Policy Guidelines and the Role of the Courts in Regulating Government" (2003) 40 *Alta L Rev* 867 at 873. See also Joan Gilmour and Diane L. Martin, "Women's Poverty, Women's Health: The Role of Access to Justice" in Penny Van Esterick ed, *Head, Heart, and Hand Partnerships for Women's Health in Canadian Environments* (Toronto: National Network on Environments and Women's Health, 2003).

⁹³⁴ Jane Raca, "Every Disabled Child Matters", *Huffington Post* (17 November 2013) online: *Huffington Post* <http://www.huffingtonpost.co.uk/jane-raca/every-disabled-child-matters_b_4108255.html>.

⁹³⁵ See Pottie & Sossin, *supra* note 498 at 151.

⁹³⁶ As was apparent in *J.R.B. v C.F.B.*, 1999 ABQB 254, 48 RFL (4th) 263 [*J.R.B.*] where the judge referred to three cases with some aspects of applicability.

⁹³⁷ As seen in the *Nieberg* case for example, discussed below.

resources that many mothers may not possess.⁹³⁸ This situation permits inappropriate administrative practices to go unchecked. Without recognition of government's legal obligation to provide support, there need not be an account-giving to mothers with disabled children. If there was recognition of a positive constitutional obligation owing on governments to implement supports that ensure the needs of mothers with severely disabled children are met, then the system would have to be accountable. But such an obligation has not been recognized. Without this recognition, provincial support law needs to have teeth to ensure support is enforced. Social policy needs to have a much different bureaucratic approach. It would include clear regulations and provisions and speedy reviews of negative decisions.

Pottie and Sossin echo Prince's opinion as to challenges posed by weak government accountability⁹³⁹ to social benefit applicants. It is in the setting of administrative discretion, where provincial programs stipulate that a decision-maker *may* provide support that serious problems for support-seeking mothers often arise. For those applicants the state refuses or gives low levels of support to, redress is not a simple matter.

Next, I discuss cases where mothers have sued government in the face of denials of needed support. I argue that in so doing, mothers confront myths that uphold the rationales for denials of needed support. While contemplating the facts and the claims in the cases examined, one must consider the psychological costs of litigating, what Chesler refers to in the setting of mothers as "the price of battle".⁹⁴⁰ Chesler characterizes this price as constituting a victimization of embattled mothers,⁹⁴¹ in the process of confronting patriarchal law. One can draw from her statement that patriarchal, as well as ableist law, have not supported the notion "that each child's life is equal", particularly in the case of severely disabled children requiring maternally complex care, where it is often a challenge to formulate a claim even if mothers have the wherewithal to bring one.⁹⁴²

⁹³⁸ See discussions in Gilmour & Martin *supra* note 933. Caregiving mothers are often simply too overwhelmed to commence any form of dispute. This is my situation presently. I am in a dispute with an institution regarding the standard of care provided to my very ill son. I question whether its worth the energy involved to pursue my complaint. I have received a number of responses and I can see this is going to be an uphill battle.

⁹³⁹ Pottie & Sossin, *supra* note 498 at 185.

⁹⁴⁰ In Chesler's research on mothers litigating in custody disputes, the psychological costs of litigation included maternal: alcoholism; immune deficiency conditions; a brain tumor; psychological breakdowns, and suicide attempts. The risk of and reality of custody loss is likewise an issue in public law in the context of caring for severely disabled children. See Chesler, *supra* note 23 at 187.

⁹⁴¹ *Ibid* at xi.

⁹⁴² Chesler alludes to some legal difficulties where non-normative children are concerned, for example, they are not readily adoptable. *Ibid* at 242-244.

Litigating the Myths

Myths as Barriers to Support

As noted previously, legal, political, and social myths work to maintain the status quo, whereby care burdens for mothers are represented as positive. Myths, embedded as they are in law, thus conceal mothers' social and political realities, and may render it impossible for them to name an identifiable legal issue in order to assert legal rights through a sound claim.⁹⁴³ Among the legal myths that arise in the setting of care for severely disabled children are those of maternal autonomy, child abandonment and child protection. Within these areas are cultural tropes concerning extraordinary mothers and failed mothers. In the political-economic domain, myths include that of a benevolent welfare state, adequately supporting those in need. The myth of a benevolent welfare state includes the myth of a state-family partnership in the areas of disability income support and respite. Both of these are discussed as though they are included under universal health care.

The myth of state-family partnership itself contains the secondary myth that it is "family" with whom the state partners, when it is primarily mothers with whom the state interacts on issues of child disability support. However, even where it is fathers who (rarely) do so, this particular myth remains in place. I have discussed this issue with a father who was involved in care of a child with a rare condition, who relayed that he challenged the myth of "family care" with a bureaucrat, informing the individual that he and his wife had no family in the province.

Myths do not have tidy boundaries; in reality, many of those I address weave together. I argue that myths combine and collude to serve the interests of those who seek to avoid obligations to provide support. In the next chapter, these evaders will be identified as potential payors of disabled child and caregiving mother support. In this chapter, the evaders are identified as instruments of the state.

Remarkably, it is widely accepted that government and a percentage of fathers do not like paying support. The low level of stigma attached to the expression of this sentiment in either case is astonishing. In the following section, to demonstrate my claim that myths are at play in public support law, I show how they appear, are used, or challenged, and by whom. I do so by referring to a variety of legal cases where mothers have litigated for support. I begin with the troublesome myth of autonomy.

⁹⁴³ For a discussion of naming a claim in the setting of social justice, see William L. F. Felstiner, Richard L. Abel & Austin Sarat, "The Emergence and Transformation of Disputes: Naming, Blaming, Claiming" (1980-1981) 15 *Law & Soc'y Rev* 631. This issue was apparent in the *Larcade* case where adequacy of one of the claims and the pleadings were stated to be flawed by the divisional court in that matter.

The Myth of Maternal Autonomy

Herring succinctly states that “one of the central rights in the liberal world is autonomy.”⁹⁴⁴ He also relays that liberal autonomy relates directly to choice and to the ability to shape one’s path in life.⁹⁴⁵ Herring’s iteration must be borne in mind in considering the situation of mothers with severely disabled children.

Liberal autonomy is to be distinguished from other forms or understandings of autonomy, such as relational autonomy, which accounts for the influences of relational interests on the self as less bounded, and decision-making as necessarily involving others’ needs. As seen throughout the dissertation, mothers support their severely disabled children unto the point of breakdown (physical, mental, emotional). This signals their not having acted in the interest of the autonomous individual woman. She has prioritized someone else, her child(ren). Like Freire, Nedelsky refers to the presence of myths, theorizing the existence of mythical legal structures premised on liberalism. She articulates that in the myth of the bounded legal self, rights delineate and protect the legal self, and the boundaries of the state.⁹⁴⁶ This articulation of rights is seen to create and to support a notion of autonomy that Nedelsky asserts is not attainable for many, including, I add, caregiving mothers. Thus liberal notions of autonomy cannot comprise a foundation on which to build a feminist legal theory of support for mothers with severely disabled children.⁹⁴⁷ Nor does such a notion “fit” with the support needs of severely disabled children and their mothers.

Maternal support claims run into conceptual difficulty because the support being sought is in relation to care, which is not to do with a bounded self, but to do with selves, plural and inter-connected. Nedelsky asserts that in actuality, autonomy is only made possible by relationships, including institutional ones. Moreover, she points out that the autonomy attributed to the self as bounded runs into difficulty in precisely those areas where women’s needs are being adjudicated by the state. She illustrates this in examples involving mothers and disabled children, referring to legislation and Court cases.

Earlier I noted the problem with the liberal conceptualization of autonomy as expressed in law. It is a form of autonomy that assigns right to individuals. These rights confer varying abilities, such as the right to enter into contracts, and to further individual interests. I also discussed an alternate conceptualization of autonomy, namely relational autonomy. As theorized by Nedelsky, autonomy is a capacity that is not bounded in the individual, rather it is situated and supported in relationships. I have not used relational autonomy as a conceptual framework, although I agree with its premises. In this section, I refer to both classic liberal autonomy (CLA) and relational autonomy (RA), as I have not been

⁹⁴⁴ Herring, *supra* note 99 at 71.

⁹⁴⁵ *Ibid* at 72. Referencing Lorraine Code, Herring notes that the autonomous man is someone who is self-sufficient, independent and self-reliant, self-realizing and acts to further his individual gain.

⁹⁴⁶ Nedelsky, *Law’s Relations*, *supra* note 191 at 93.

⁹⁴⁷ *Ibid* at 118. Nedelsky specifically states Anglo-American liberalism cannot meet the aspirations of a feminist theory.

able to ‘do away with’ mention of CLA entirely, as it is the concept that undergirds rights in the various legal cases I discuss.

I first mention the case of an Ontario mother and physician, Nicole Desmarais. She requested a voluntary special need agreement under Part II of the *Child and Family Services Act (CFSA)*, for her severely disabled son, and her request was denied.⁹⁴⁸ She subsequently brought an application to be permitted to access one through a court order.⁹⁴⁹ She also went to the media with her complaint as to lack of support in her case.⁹⁵⁰ This case can assist with understanding the problems with CLA. Desmarais sought a *shared* care agreement with the state. Thus, it was a relational provision she was relying on, and granting it would have supported not only Desmarais, but all of her children, as well. In refusing to provide it to the mother, who was the assumed CLA legal subject, the state reneged on its responsibility for a form of *relational* support.

Nedelsky points out that the law constitutes relations in society, but the *Desmarais* case (like the earlier litigation of Anne Larcade) showed that some relations in society (mothers like Desmarais and Larcade) are left out of law. This is so even where the law has included them, since the government was choosing not to provide special needs agreements to anyone. In terms of enacting CLA, Desmarais was struggling with that, because she and her other children could not care for her severely disabled son. We do not know whether (like Larcade before her) Ontario made an offer, out of court, to provide care in settlement of her claim. Such settlements are concerning, as they contradict the assertion that the state is not funding/providing such care. In some assumedly only unusual cases the state does in fact provide care in this case to certain mothers who decide to sue.

Another point I want to make is that even extreme *outlier*, financially autonomous mothers (in the CLA sense) run into difficulty with the unjust way in which their achieved CLA is dealt with in disability support policy. *Tali Lalkin v Director, Ontario Disability Support Program* is instructive.⁹⁵¹ Lalkin found herself embroiled in disputes with the province. Lalkin, who argued that the Director had failed to take into account her unique circumstances in 2013, won her appeal to be granted a higher amount of support than the suggested guideline ceiling set by the Ministry’s policy, which was an income of \$63,100.⁹⁵² Her gross annual income in 2012 was \$101,734. She had previously had the same battle with the Assistance

⁹⁴⁸ *Child and Family Services Act*, RSO 1990, c C.11

⁹⁴⁹ Appendix H

⁹⁵⁰ *Desmarais v Ontario*, (MCYS) 2014 Ontario. The application was filed, but not pursued. I tried to reach Dr. Desmarais in 2015 at her office, to ask for a copy of her application and the court file number, but was not successful.

⁹⁵¹ *Lalkin v Director, Ontario Disability Support Program*, 2013 OSBT 5527 (CanLII).

⁹⁵² An issue that arises is whether in fact her circumstances are in fact ‘unique’ or whether such expenses are actually quite common. Her son is described in the decision as having “severe cerebral palsy”. The point is that children who have severe disabilities, for whom the ACSD program was put in place, may incur massive care related costs. *Lalkin* is not unlike *Wood*, *supra* note 865, which also dealt with the purported ceiling in the policy guidelines.

for Children with Severe Disabilities Program Director four years earlier. The Tribunal Member at the 2008 hearing of a similar appeal, decided Lalkin was entitled to a higher than guideline amount of funding. The evidence Lalkin presented in 2013 showed that her expenses in caring for her son cost her \$40,000 a year.⁹⁵³ The 2013 Tribunal member, Brian Brown, commented on the fact that after taxes, 50% of her income was spent on meeting her disabled son's needs, and that in spite of a higher income, she struggled to make ends meet. It was held, twice, that on the balance of probabilities, she had established the decision of the Director was wrong. One can see that as a successful lone mother with a six-figure income, an income level double what most men in Canada earn on average, she alone is expected by the government to absorb the exorbitant costs of disability care. *Lalkin* is a useful myth challenger. Ms. Lalkin had a healthy income, thus she cannot be portrayed as a financially incompetent mother. Nor can she be faulted for a failure to be independent and autonomous. She has a career. She is also on-task with regards to her disabled child's needs.

Again and again, Directors insist that a cap exists on funding. Section 49 of the *ODSP Act* provides that the Director may provide financial assistance in accordance with the regulations to a person who meets the prescribed criteria to assist with extraordinary costs related to a child with a severe disability. It is set at an annual income of \$63,000 approximately, a cap that in instances is seen to 'prevent' bureaucrats from meeting their mandate. Yet, as the tribunal member in *Lalkin* noted, it is not binding, *as it is only policy*.⁹⁵⁴ Lalkin reveals that disputes comprise an additional burden that mothers carry while they perform maternally complex care, which is that they may be required to prove their need of high levels of support for very disabled children, repeatedly. The *Lalkin* Tribunal commented that the ACSD program guidelines ought not to be applied arbitrarily without due consideration of factors provided in the legislation, and held her circumstances warranted support.⁹⁵⁵ Thus Lalkin had battled for and 'won' a \$5,400 state contribution towards the 50% reduction of her six-figure income, with the financial burden discussed comprising only one of many that she bore.⁹⁵⁶ This case shows that even if a mother earns income that would otherwise permit her to meet the ideal of CLA, she cannot live out the ideal so long as she is in relationship with her severely disabled child(ren) in today's legal arrangements. This is because it is mothers, and not the state, who have been responsibilized for care. Were the state

⁹⁵³ This is the same amount that the parent in *G.E.*, *supra* note 923 at para 3, stated one of his sons required for an 11-month period. It is important to take notice of quanta in all of the cases in this area because amounts requested reflect the minimum some parents state they require and that is important in relation to my recommendations.

⁹⁵⁴ The Directors order was rescinded and she was awarded the full \$450 a month of state support, *Lalkin*, *supra* note ## at para 17.

⁹⁵⁵ *Ibid* at para 14.

⁹⁵⁶ *Lalkin* also reveals that to fully understand what is taking place outside the law, one must also look at what is taking place inside it. The literature shows that mothers with children experience greater economic hardship, however it is when one looks at what happens when they actively challenge the status quo and the legal requirements of disclosure to do that, that one sees the obstacles they face and the paltry amounts of support provided.

supporting the relationship of this single divorced mother with her three children, one of whom has severe cerebral palsy,⁹⁵⁷ they would *all* have realizable legal entitlements to support, and Ms. Lalkin would not find herself (self-represented) in a dispute with the province regarding money.

In order to illustrate this point further in the Canadian context, I next examine two Canadian cases that provide information about how the state sees mothers with disabled dependents requiring care.

In *Ontario Disability Support Program v Favrod*, the parents had an agreement whereby the father paid the mother “child support”, with which he complied.⁹⁵⁸ When the child turned 18, the adult ‘child’ applied for ODSP. The Director of the program sought to have the father’s payment to the mother be treated as income paid to or on behalf of the child, and therefore to have it deducted from the provincial disability support payment. The father’s view was that mother and daughter required support beyond what ODSP paid.⁹⁵⁹ The daughter appealed to the Ontario Social Benefit Tribunal, which held that payments made to the mother were the mother’s income under the provisions, and not income to be attributed to the young woman. The Director appealed but the appeal was denied. The *Favrod* court held that “The circumstances here are important in that the parents have endeavoured, through their actions and agreement, to share in the responsibilities involved in providing quality care for their daughter.”⁹⁶⁰ The court opined that the mother used the money “to assist her in meeting the exceptional needs of caring for a person with a disability.”⁹⁶¹ The judge observed that the father’s obligation to pay ended with the mother’s death, and incurred no tax consequence. The judge called this payment a spousal support-like provision.⁹⁶² The term “income support” that was being paid to or on behalf of the daughter makes it sound as though the disabled 18 year-old was living independently on her state support of \$13,392 annually. Obviously, this amount could not support someone in need of full-time and intensive disability-related care. Ontario Disability Support practice at the time of the decision was that child support was subject to state clawback. However, this payment to the mother was decided by the tribunal to be compensation for the monies paid for her assisting in caring for the adult disabled child.⁹⁶³ Within the

⁹⁵⁷ *Lalkin supra* 951 at para 8.

⁹⁵⁸ He complied with the payments both before and after his daughter turned 18. *Ontario Disability Support Program v Favrod*, 208 OAC 360 at para 3, 2006 CanLII 4898 (ON SCDC) [*Favrod*]. ONSCJ

⁹⁵⁹ ARCH Alert states the young woman lived with both parents, but does not break down the hours. Katherine Haist, “Support Payments to Parent of Adult ODSP Recipients Declared Parent’s Income” (10 March 2006) *Arch Alert* 17.

⁹⁶⁰ *Favrod, supra* note 958 at para 15.

⁹⁶¹ *Ibid.*

⁹⁶² She used a feeding tube for nourishment, and was incontinent thus requiring toileting support. She had many support needs, which would have affected the mother’s ability to earn income. Ontario provided \$708 per month, and the father provided \$275 per month (later \$300 per month). *ibid* at paras 2-4. This young woman, under an income support act that “paid to or on behalf of, or for the benefit of” was provided \$13,392 per annum by the state and father combined (after a battle for that full amount), about half the low income cut off and clearly presuming other forms of unarticulated support from elsewhere.

⁹⁶³ *Favrod, supra* note 958 at para 5.

confines of the state clawing back meager amounts of money that a father willingly paid to a caregiving mother, who did not herself receive social benefits, the court made a *just* decision. However, the court's statement lauding that the parents "shared" responsibilities for care of their severely disabled adult child (which looks like support of their relationship) may not have been reflective of who did the lion's share of care work. Michelle Favrod had custody and the father had access, he was able to be in paid employment, the mother was not. The practice of looking at the mother's income as separate from the severely disabled daughter she cares for and supports lacks credible basis. This mother in the result lacked CLA and Relational Autonomy.

Favrod is important because it underscores that the issues are greater than merely that of the state requiring mothers to pursue private avenues of support before public support will be provided. This mother had already done that, and that support came under siege, with Ontario conflating the child support to the mother with the disabled adult's support from the state. It is as if the state views caregiving mothers as "getting away with" accessing money, to which they are not entitled. However, another way of looking at it is to note that the state is getting away with unremunerated care, to which it is not entitled.

The myth of the autonomous so-called adult severely disabled child, an issue I later address, feeds state policy that denies severely disabled children support when they reach legal adulthood, in this situation a legal status with ableist assumptions informing it, which are used against support seeking mothers, as will also be seen in the next chapter.

Another Ontario case dealing with a disability income support program trying to reduce disability support to an adult child with a disability is *Ontario (Disability Support Program) v Ansell*.⁹⁶⁴ This case involved a young woman, Jocelyn Ansell, who also lived with her single mother. The mother received \$800 a month in child support from the father.⁹⁶⁵ At age 18, Jocelyn applied for provincial disability support. The program Director determined that child support payments were income attributable to Jocelyn. As the facts state, Jocelyn's father's obligation terminated if Jocelyn stopped being a full-time student, stopped living with her mother, or if her mother died. The court noted that the Director had assessed Jocelyn as independent and not as a dependent. "However, under s 37(1) of the Regulation – the key provision on this appeal – any payments to her or on her behalf or for her benefit constitute income and so, under s 29(1), they must be deducted from the income support otherwise payable to her."⁹⁶⁶

⁹⁶⁴ *Ontario (Disability Support Program) v Ansell*, 2011 ONCA 309, 281 OAC 224 [*Ansell*]. The daughter was the litigant but the subject matter was payments to her mother from her father. This case calls attention to recognition of relationality as a missing piece in support law.

⁹⁶⁵ *Ibid*, at para 4, records that Jocelyn's "parents separated in 2002, when she was 12 years old. Jocelyn's mother claimed that her husband was abusive and refused to recognize their daughter's disability. Since separation, Jocelyn has lived with her mother."

⁹⁶⁶ *Ibid*, at para 13.

Jocelyn's argument was that the position of the Director was unfair to single mothers, *and undermined the idea of shared responsibility*, a stated feature of the ODSP provisions. The Ontario Court of Appeal found that the focus of the Director ought to have been on exemptions under s 43. Section 43(1) exempts gifts or other voluntary payments of an unlimited amount as long as they are applied to expenses for disability-related items and are approved by the Director of the program.

The Court agreed with the position taken by Jocelyn-- that the child support order stipulated the support is paid to the mother, and that as the order did not specify how the mother was to use the money, she was not obligated to use the money on disability expenses. Jocelyn's mother was thus not required to account for how she spent it; moreover, the mother had to report the support on *her* income tax return, not on Jocelyn's return. The court added that the child support payments were tied to the mother, ending if she died. It stated that Jocelyn was not a party to the court order and had no legal right to enforce it. Therefore, the Ontario government program could not ask the mother to account for her use of the support paid to her by the father.

In both *Favrod* and *Ansell*, caregiving mothers are put on the defensive, needing to defend against the state taking away their child support, because the state is paying meagre disability income support to their adult disabled children. It is possible that the state views these two things as mutually exclusive. If bureaucrats insist on ignoring that care is being provided to legal adults, as well as income support from the state, it may appear that way.

Mothers have described the situation in Ontario *vis-à-vis* ODSP and their private support provisions as oppressive.⁹⁶⁷ Ontario provides a pittance to disabled adults, having taken steps to ensure that the costs of care are privatized to the greatest extent possible, without regard to hardship, or its role in diminishing women's equality.⁹⁶⁸ Tolmie and Bachmeier's submission to their MPP entitled *Increasing the Burden Instead of Lightening the Load: The Impact of Current ODSP Policies and Practices on Single Parents Caring for Adult Children with Disabilities*, reflects an acquired awareness that government policy makes things less, not more, equitable, for mothers. There is a curious inconsistency in caregiving mothers' dealings with state support. Mothers must choose to pursue their individual support claims through public or private law. Once in these areas, however, their and their children's support is

⁹⁶⁷ See M. Tolmie & Steward A. Bachmeier, *Increasing the Burden Instead of Lightening the Load: The Impact of Current ODSP Policies and Practices on Single Parents Caring for Adult Children with Disabilities*, Submission to The Honourable Sandra Pupatello MPP for Windsor West (2005) [unpublished].

⁹⁶⁸ The preamble to the Ontario Disability Support Program refers to assisting people with disabilities to live, work and participate in their communities. The *ODSPA*, *supra* note 756, does not address mother's rights nor does it address people who are unable to work. This latter feature has not attracted attention I argue because it "fits" with a social model of disability rights perspective, which advances the view that society disables. The Program promotes itself as facilitative of inclusion. Yet, the Program is also silent on issues concerning (for example) youth with severe impairments in need of ongoing support.

not dealt with as though each is legally autonomous. This is both vexatious,⁹⁶⁹ and also a legal vestige of an era when women and children were together considered dependents.

If Herring is correct, and autonomy is a core “right” in our society, clearly it is one being denied to mothers providing this form of disability care in current policy settings. In being tasked with providing life-long disability support, such as the situation described in *Favrod*, the version of autonomy our legal system purports to uphold is being denied to mothers with severely disabled children, who are denied the right to exercise choices in order to shape their own lives. A looming question is whether Michelle Favrod would like to have done something other than to provide sole-support care and remain poor.

Finally, in this section I examine examples of harsh expectations of the state that caregivers exhibit CLA, when the legal trouble they are in has to do with support. I turn first to an older criminal law case, concerning a mother with medically disabled children also having to deal with complications of receiving state support. This case shows that the pursuit of a scintilla of CLA independence on behalf of a welfare recipient’s medically disabled children is viewed as suspect by the state. In *R v Bond*⁹⁷⁰ one can see that CLA is not something the state fosters for caregiving mothers. *Bond* illustrates the complex cross-cutting nature of problems mothers deal with legally.⁹⁷¹ Single mother, Donna Bond, was charged with ‘welfare fraud’ for allegedly defrauding the province of Ontario.⁹⁷² The basis for the allegation was that she had a bank account she had not reported on required government documents. She testified that she had saved money from ‘piece-work’, from her ‘baby bonus,’ and her tax refunds, and that she had formally informed officials. She also gave testimony that the serious health problems of her children caused her to realize that they “will require financial assistance to deal with these problems in the years ahead.”⁹⁷³ As a result, she created a fund for them.

When her fund was ‘discovered’, Bond stated she had ‘honestly believed that she did not have to report the savings because they were for the children’.⁹⁷⁴ In *Bond* it can be seen that the mother was constructed as a criminal.⁹⁷⁵ She struggled to care with forethought, by saving to provide as security for

⁹⁶⁹ Shelley Gavigan writes about the vexing relationship between family law and the administration of social benefits, especially for lower income women. Shelley Gavigan, “Something Old, Something New? Re-Theorizing Patriarchal Relations and Privatization from the Outskirts of Family Law” (2012) 13:1 *Theor Inq L* 271 at 294.

⁹⁷⁰ *R v Bond* [1994] OJ No 2185 (QL) (ONCJ) [*Bond*].

⁹⁷¹ *Bond ibid*

⁹⁷² She was found guilty of welfare fraud. As noted in the decision, the Judge held “Her commendable frugality and selfless motives, as well as the paradoxes inherent in her conviction, were matters for sentencing.” Even “good” mothers have struggled with support law. *Ibid* at para 1.

⁹⁷³ *Ibid* at para 8. The case itself refers to the “serious health problems of both her children”, *ibid*, but the decision does not elaborate as to what their conditions were.

⁹⁷⁴ *Ibid* at para 13. For a discussion of *Bond* case, see Gavigan & Chunn, *supra* note 203 at 221.

⁹⁷⁵ Compare what happened to Donna Bond with what happened to another mother receiving welfare, Debbie Peliti. Peliti who had a large family, including a medically disabled child, found a large sum of money and returned it to the bank. Of this case, then Premier McGuinty stated to the press “[i]t is just so important for us to send the right signal.” The at once infantilizing and responsabilizing meta-message in the cases of single mothers

children with health problems. What little security she built, the state took away, and then punished her for it. In *Bond* the mother was trapped by her legally constructed circumstances, and by the characterization of her as a law-breaker. Bond's efforts had been directed towards acquiring a low level of autonomy and independence, to be provided to her children, something not possible within the legal framework she was forced to operate within.

Bond was reported to media at the time it was decided and she had to endure public notoriety, too.⁹⁷⁶ Her situation could have been an instructive one that educated government about the plight of poor, caregiving mothers, but instead, that feature of her life was treated as an accessory to the main issue, which was that she was legally deceitful. A different reading of the case would be that caregiving mothers live with extreme concern about the future welfare of their medically disabled children, and that what the state provides is grossly inadequate to address their legitimate concerns. Janet Mosher has argued that the treatment of Donna Bond is consistent with the state's approach to welfare fraud generally. She argues that in the criminal proceedings against Bond, the law of fraud was inappropriately applied.⁹⁷⁷

Myth of Deinstitutionalization

In the aftermath of the disability rights movement to ensure the deinstitutionalization of disabled children, institutionalization is widely considered to be a thing of the past in Canada. Although it is no longer a common practice to place disabled children in large institutions as matter of course, severely disabled children are still placed into state care. This occurs through law in three distinct ways. One is where there have been allegations by the state of child abuse or neglect (a large category). Another is when often competent but exhausted mothers agree to "abandon" their children, and I address this legal practice in the next section, under the myth of abandonment.

Here I address a third pathway to institutionalization of disabled children that may be thought of as a form of disability 'double jeopardy'. This situation has to do with child protection applications brought in relation to disabled children *whose mothers* are intellectually or psychiatrically disabled. This situation has to do with disabled and otherwise 'high needs' children.⁹⁷⁸ I note here that there will be at times, a disability 'triple jeopardy' within this group. The BC Report, *Broken Promises*, revealed that

Donna Bond and Debbie Peliti was that 'good' caregiving mothers, however impoverished, do not take money. See Richard Brennan. Honest Mother's \$40,000 Escape. December 10, 2004.

Online http://www.ottawamenscentre.com/news/20041210_honest_mothers.htm.

⁹⁷⁶ See for example "Welfare Mom Saved \$22,527. Judge Orders Her to Teach Others" *Toronto Star* (21 Sept 1994) A2.

⁹⁷⁷ Mosher, Janet E., "Welfare Fraud: The Constitution of Social Assistance as Crime" (2005). *Commissioned Reports, Studies and Public Policy Documents*. Paper 161.

<http://digitalcommons.osgoode.yorku.ca/reports/161>, at 33.

⁹⁷⁸ Isabel Grant, Judith Mosoff, Susan B. Boyd and Ruben Lindy "Intersecting Challenges: Mothers and Child Protection Law in BC" 50:2 UBC L Rev 435.

some mothers involved with child protection were themselves raised in state homes designated as ‘special needs’.⁹⁷⁹ This means that some mentally disabled mothers were raised in institutional settings.

Legal cases show that intellectually or psychiatrically disabled mothers are at increased risk of losing their children. Children are found to be in need of protection because of the view that mothers with mental disabilities are unable to meet the needs of their child. In some of these cases as Grant et al show, a judge may find that the mother is ‘unfit’ where the child also has a disability in fact situations where, in the absence of a special need in the child, the child would be returned to his or her mother.⁹⁸⁰ This situation reveals that although adult disabled women are no longer being routinely institutionalized themselves their disabled children are. Based on findings in legal cases, and scholarly work, mentally disabled mothers are excluded from the normative institution of motherhood, not unlike other mothers with non-normative children.

Twenty years ago Judith Mosoff (mentioned in a prior discussion on child welfare supports), pioneered legal analysis at the intersection of child protection and psychiatrically disabled mothers. The issues that arose then arise now. Isabel Grant, Judith Mosoff, Susan B. Boyd and Ruben Lindy,⁹⁸¹ in more recent research, examine British Columbia decisions that provide examples of mothers with intellectual and psychiatric disabilities coming to the attention of child welfare *because they are disabled*, and being legally challenged to retain custody of their children. In particular they describe how courts adjudicate the child protection litigation these disabled mothers are trapped in.

As stated, Grant et al’s examination reveals judges who state they would return a child to a disabled mother, were the child not special needs or high needs.⁹⁸² Since the mother is disabled they conclude the also disabled child is in need of protection. Decisions they examined reveal that this approach is based on the belief that mothers with disabled children require better than average skills to provide the care needed to meet the best interests of the disabled child. Grant et al. refer to this as the requirement of “exceptional parenting.”⁹⁸³ This judicial discourse represents *cloaked* status recognition by child protection courts. They appear to recognize mothering and caregiving are two separate things.

In *CAS v L.T. and R.S.*, a mildly intellectually impaired mother, sought to have her disabled child returned to her and the father of the child. The court opined that the multiply disabled child required high quality parenting, and caregivers who would be capable of advocating for community resources long term.⁹⁸⁴ In this case the child was found to be in need of protection, and returned to the mother subject to

⁹⁷⁹ *Pivot* at 101 *supra* note 190

⁹⁸⁰ Grant et al. *supra* note 978 (no pagination)

⁹⁸¹ Isabel Grant et al *supra* note 978

⁹⁸² See for example, Grant *ibid* (no pagination)

⁹⁸³ Grant *supra* note 987.

⁹⁸⁴ See *CAS v L.T. and R.S.* 2013 ONSC 6512, in which a mildly intellectually impaired mother, along with her mildly intellectually impaired partner, sought to have their disabled child returned to their care. The court opined

a stringent society supervision order. Although some of the terms of the order can be construed as a form of support, court orders carry the taint of domestic policing. This case also relays that having a disabled/high needs child places mentally disabled mothers at increased risk of disabled child loss to the state or to what courts perceives to be a better arrangement.

Grant et al.⁹⁸⁵ state that a central question in child protection at the intersection of disability, and mothering, is the extent to which the province is responsible for providing supports that would enable intellectually or psychiatrically disabled mothers to parent children with “special needs”. My project has not focused on child welfare support to *disabled* mothers, but in the context of child welfare and *disabled* children, disabled mothers’ legal rights to support become relevant. If a disabled mother does not realize her right to support, then her disabled child will not be able to realize his or her best interests. The best interests of the child is a foundational principle in Canadian child welfare law.⁹⁸⁶ Moreover, Article 3(1) of the CRC provides that in all actions concerning children undertaken, whether by public or private social welfare institutions, courts of law or administrative authorities, best interests of the child must be a primary consideration.⁹⁸⁷ What is at stake is a child being taken into state care, to live in the shadow of state watchdogs, which is institutional living, not community living. For mentally disabled mothers to be able to provide care, the *CFSA* ought to be fulfilling its mandate to find the least intrusive means to support mentally disabled mothers with disabled children, but is not, based on findings of British Columbia legal research by Grant et al.⁹⁸⁸ Their findings should inform Ontario legal practice and jurisprudence, given that best interest of the child is a legal tenet and not a provincial expression of law. It should do so likewise given that disabled people have the right to equal treatment in law. Disabled mothers ought to be accommodated, something that is legally recognized in United States child welfare law.⁹⁸⁹

There is stigma associated with being a mother with mental disabilities, in conjunction with the stigma of having a disabled child, and the stigma of having been served with a child protection application is considerable. Yet these mothers have been responsabilized with care without regard to their circumstances. This problem also attaches to non-mentally disabled mothers with severely disabled children. The stigma is an outcome of how ordinary motherhood is constructed. It is such that mothers

that the child required high quality parenting, and caregivers who would be capable of could advocating for community resources for her on a long term basis.

⁹⁸⁵ Grant et al *supra* at note 978.

⁹⁸⁶ See express mandates of Canadian provincial and territorial child welfare statutes.

⁹⁸⁷ CRC *supra* note 880

⁹⁸⁸ *Ibid*

⁹⁸⁹ This is well articulated in a series of modules for social workers in Minesto. See Elizabeth Lightfoot and Mingyang Zheng. Parents with Disabilities in Child Welfare. July 25, 2018. Centre For Advanced Studies in Child Welfare. Online< <https://www.youtube.com/watch?v=P88ujqsuxjw>>

ought not to require state support. If she does, then, to use Freire's words, she is crushed, diminished, and maneuvered by myths.⁹⁹⁰

Yet, in terms of being maneuvered by myths, some intellectually and psychiatrically disabled mothers serve a reply to a child protection application, they attend court, and they do put themselves through a harrowing legal process that constructs them as unsuited to caring for their children. Moreover, in spite of the well-known involvement of child welfare in the lives of mentally disabled mothers, research involving intellectually disabled mothers being conducted in Toronto found mothers do not agree with how social workers characterize their capacity or skills. They state they are misjudged and overly criticized and are that they are perceived as less competent than they are. Although they are being legally maneuvered by powerful myths, they appear to be cognizant of that and they resist.⁹⁹¹

Interacting Myths of Abandonment and Child Protection

The myth of abandonment and the myth that the severely disabled child is in need for protection loom large in the area of care for disabled children. These are sustained in law by how it deals with mothers with disabled children. Legal terms reinforce the myth of the need for protection where severely disabled children are concerned. For example, being in the charge of an adult is a fundamental feature of being a child, or being deemed incapable of self-support in law. Moreover, a child is by definition in the "charge" of *either* the state *or* a private party. State child protection law was created to provide for children who have no parents or whose parents are "bad". In Canada, provincial child protection legislation contains grounds for involuntary state intervention in families in order to protect children at risk of neglect or abuse. Pursuant to s15(2) of the *CFSA*⁹⁹², child welfare societies which are agencies designated by the Minister, may proceed by way of immediate apprehension or by bringing an application to court seeking interventions and/or a parenting plan to ensure the safety and well-being of a child alleged to be at-risk. These powers are set out in s 37(2) (a) and (b) of the *CFSA*. These sections specify in subsections (a) through (m) the grounds upon which a child may be found in need of protection. These include if a child has suffered, or if a child is at risk of suffering, physical harm, where the individual having charge of the child has failed to adequately care for, provide for, supervise or protect the child or there is a pattern of neglect in caring for, providing for, supervising or protecting the child. These are itemized as where a child has or is at risk of: sexual exploitation; unmet need of medical treatment; emotional harms that a parent or individual with charge of the child has not sought to remedy, a mental or developmental

⁹⁹⁰ Freire [Education] *supra* note133 at 5

⁹⁹¹ The Voices of Mothers with Intellectual Disabilities and /or Developmental Disabilities (IDD). Lecture given November 2017 at York University Faculty of Health, Chair in Women's Mental Health, by Marina Heifetz based on research undertaken by Yona Lunsky, Hilary Brown and Marina Heifetz.

⁹⁹² *Child and Family Service Act* *supra* note 817. This *Act* has been replaced. The replacement likewise has provisions for apprehension by way of a warrant and by bringing an application.

condition that if not remedied could impair the child's development: has been abandoned where the parent has died, is unavailable, unable or unwilling to exercise custodial rights and is over age 12 and being encouraged by a parent or person with charge has encouraged or failed to supervise a child who has injured someone. Section 37(3) lists the circumstances to be taken into account by the decision maker in making a determination regarding state care.

It is to be noted that women in poverty are caught in the net of government child protection proceedings. Features of life in poverty overlap with the framing of maternal neglect in child welfare. As a result there is disproportionate representation in care of First Nations children.⁹⁹³ Those at risk of homelessness or who are homeless also come to the attention of child welfare agencies.⁹⁹⁴ As do mothers with disabled children, as I have stated.

One might argue that state law has focused on child maltreatment, and this is why child welfare law did not anticipate the kinds of support that severely disabled children need. However, there was once another set of laws pertaining to children provided for by the state: laws governing the large institutions to which disabled children were at one time committed. Once those laws were repealed, child welfare legislation remained. At the time when deinstitutionalization was taking place, provisions were put into child welfare statutes pertaining to the provision of disability care.⁹⁹⁵ However this took place at a time when thinking of medically disabled children as a new form of childhood had not yet come fully into being. So, in a sense, the state's child welfare amendments may not have anticipated this group, even as it did consider other severely disabled children. In fact, a child is defined differently in different statutes, in keeping with the purposes of the legislation.⁹⁹⁶ I argue that present-day legal definitions of the 'child' present problems to mothers with disabled children in public and private law. For example, some such legal definitions bar them from obtaining needed support in private law, as in the *Vivian* and in *J.M.S.* cases discussed below.

Mothers who cannot obtain adequate support from the state or from another parent may 'agree' that their child is in need of 'protection' when in fact, their child or they, themselves, are only in need of

⁹⁹³ This has been widely addressed in the literature, in the work of Cindy Blackstock, Nico Trocm and others.

⁹⁹⁴ See for example Sylvia Novac, Emily Paradis, Joyce Brown, and Heather Morton. Supporting Young Homeless Mothers Who Have Lost Child Custody. In: Hulchanski, J. David; Campsie, Philippa; Chau, Shirley; Hwang, Stephen; Paradis, Emily (eds.) Finding Home: Policy Options for Addressing Homelessness in Canada (e-book), Chapter 4.1. Toronto: Cities Centre, University of Toronto. www.homelesshub.ca/FindingHome

⁹⁹⁵ This is what s.30 of the Ontario *CFSA* (Special Needs Agreements) was implemented for. Parents complained that they would not be able to cope. This background history was relayed to me by the late Dawn Roper.

⁹⁹⁶ For example, in family law, under the federal *Divorce Act*, *supra* note ## at s 2(1), the legislation provides a definition for who meets the criteria of a child of the marriage. *CFSA*, *supra* note 762, s 3(1), defines a child simply as someone under the age of 18. Likewise, under the *Children's Law Reform Act*, RSO 1990, c C.12, Part III, a child is someone who is a minor. A child may also be qualified as 'mature minors' for decisional reasons.

support.⁹⁹⁷ The myth of protection hides what is taking place with respect to disabled children and how money can be made available to them. Likewise, mothers may ‘agree’ with the state that their child is “in need of protection” even though everyone concerned knows that the child is in need of a residential placement, either short-term or longer term.

Where women and law are concerned, the use of the concept of ‘protection’ has historical relevance. Kalsem states that the rhetoric of protection was central to the doctrine of *couverture*, asserting that in law, protection ultimately refers to “misery and oppression.”⁹⁹⁸ Although this reference is drawn from a different historical context, and that of matrimonial law, the use of law to ‘protect’ articulated in other legal domains has been historically problematic for poor woman and disabled people. Certainly, the Ontario Ombudsman’s Report, *Between a Rock and a Hard Place: Parents Forced to Place their Children with Severe Disabilities in the Custody of Children’s Aid Societies to Obtain Necessary Care*, would indicate that this is still the case, in at least this circumstance. In his report, mothers’ despair is exposed in every case where child protection was offered to caregiving mothers, who sought only support.

Accompanying the evocative myth of protection is the equally powerful corresponding myth of the failed mother, to which I have referred previously. This myth may be theorized to have arisen as an ableist invasion into the patriarchal institution of motherhood, a notion that corresponds with Freire’s colonial “cultural invasions”, which introduce myths to produce a particular form of consciousness.⁹⁹⁹ In the setting of my project, failed mothers are those deemed unable to provide the level of care for disabled children set by the state. Mothers placing children into state care are seen legally (and often, socially) to have failed *as mothers*. The aim of the myth of protection is to present the state’s version of protection, and to ensure mothers remain reluctant to seek it as a form of support.

Child protection has a punitive edge to it, a feature so integral to it that one barely thinks to question it. Mothers of disabled children in need of placements, but faced with the myth of a need for state protection, will have internalized the shame of failure. This myth is so powerful that I suggest mothers will risk other personal and professional losses in order not to be cloaked with it.

I now move on from the point made above that it is the state that constructs disabled children in need of care as children in need of protection, to a related point. It is that once the protection finding process is underway, or has been accomplished, serious legal conundrums arise, and these conundrums have been pointed out by litigating mothers themselves. I interpret this as a move by them towards critical

⁹⁹⁷ Having to fit one’s child into the definition of “child of the marriage” is one example, another was seen in *Vivian v Courtney*, 2013 ONSC 5090 (2013) where the mother struggled to have her child fit the definition of a child for the purposes of support.

⁹⁹⁸ Kalsem, *supra* note 38 at 25.

⁹⁹⁹ Carien Fritze, “The Theory of Paolo Freire” (St Clare’s Multifaith Housing Society, nd). She refers to this process of internalization.

consciousness. Thus I posit that mothers in the two cases I examine below may be seen to have moved out of magical consciousness, a mental state reflecting a sense of powerlessness, to one where mothers understand that contradictions in law are mechanisms that serve to oppress.¹⁰⁰⁰

As noted previously in Chapter Two, under the heading of Methodology, Freire posited that oppressed persons had to leave this mental state in order to enter the state of critical consciousness in which change could be sought. Interestingly, judges in both cases I discuss below were confronted with “good” mothers whose demands for support challenged the firm boundaries of child protection law, but who claimed their legal right to support (by way of care in both instances) anyway. In a sense the judges in these cases had to grapple with the myths apparent in these two cases. Justice Ann Molloy in the first case, *J.M.S.*¹⁰⁰¹, challenges, in her dissenting judgment, a legal myth in the *CFSA*, which requires a child to be in one of two legal statuses (child of the marriage or crown ward). Justice Sheilagh O’Connell in the second case, *J.A.1 and J.A.2*¹⁰⁰², grapples with the *CFSA* as well, resisting a simple reading of what order she can make for care.

J.M.S. v F.J.M. involved a separated mother with two children who sought child support for her disabled son. He had a severe disability and had been made a temporary ward of the province for periods of time in 1996 and again 1997. In 1998, he was made a crown ward.¹⁰⁰³ A crown ward is a child whose parents, by order of the court, no longer provide care or make custodial decisions for the child.¹⁰⁰⁴ An agreement between the mother and the child welfare agency was appended to the 1998 order for Crown Wardship. It set out that the mother was to provide \$80 of her Federal Child Tax Credit to the Children’s Aid Society, which she did. This is the Provincial government clawing back a Federal benefit to a single mother with a severely disabled child. The access agreement with the child welfare society stipulated that the mother would have her son home with her and with his non-disabled brother every other weekend, at Christmas, for March break and for half of the summer vacations. The legal arrangement made was access at the discretion of the Society pursuant to s 61(5) of the *CFSA*.¹⁰⁰⁵

¹⁰⁰⁰ Freire used the term “magical”, while Marx used the term “false”. Mother’s conform based on societal myths.

¹⁰⁰¹ *J.M.S. supra* note 15

¹⁰⁰² *Children’s Aid Society of Halton v J.A.1 & J.A.2*, 2011 ONCJ 624 [J.A.1].

¹⁰⁰³ This is the same date in which Joyce Dassonville sought state support, and the same time frame Anne Larcade was attempting to arrange for funding with the Ontario government. It was same time frame *Auton* (1999) was brought as a class action. Namely, shortly after the ending of CAP by the Federal government and when institutional care was being ever more replaced by maternal care, including for severely disabled children.

¹⁰⁰⁴ *CFSA, supra* note ##, s 63 (1) reads: Where a child is made a crown ward under paragraph 3 of subsection 57 (1) or under subsection 65.2 (1), the Crown has the rights and responsibilities of a parent for the purpose of the child’s care, custody and control and has the right to give or refuse consent to medical treatment for the child where a parent’s consent would otherwise be required, and the Crown’s powers, duties and obligations in respect of the child, except those assigned to a Director by this Act or the regulations, shall be exercised and performed by the society caring for the child.

¹⁰⁰⁵ *J.M.S. supra*, note 15, para 5.

The evidence showed the mother incurred child related costs of about \$550 a month. There was no contribution from the child's father, who argued it was the state's obligation to support his son (he did not see a reason to support his child). The mother's position was that their sons should not be treated differently from one another. I note that her view is in accordance with family law policy, which purportedly has child support set at a quantum to ensure that children with separated parents can maintain the standard of living they had prior to separation, and not have one well-off parent and one poor parent and so too for children. I analogize this ideal in matrimonial law to what occurred in *J.M.S.*, where there was a poor disabled brother in state care and a better off non-disabled brother at home living with his mother. This was not the analogy the court chose to employ however.

The majority in *J.M.S.*, in making its decision not to order the father to pay child support for his disabled son, reminded *the mother* that she was in the position of a non-custodial parent in a typical separation. She has access to her son. The court did not therefore perceive any support obligations owing from the father to the mother. In practice, even though the state took over as "the mother" (if we use the analogy of the majority), the fact remains that the biological mother continued to provide significant unremunerated maternal care, housing, disability support and financial support. The reasoning in this case, based on the legislation which I argue likens the mother to a matrimonial law access parent in relation to the state as custodial parent blurs the public-private divide in a judicially unorthodox way. Perhaps this is because there is no legal way to consider the needs of this group of mothers and children. Moreover, the question that arises is if the state is the custodial parent, and the biological mother is the access parent, where then does the biological father fit in this scenario? If the mother is described as a parent with access rights to the crown ward, how ought one to legally describe the relationship of the father to the crown ward? The fact is that the caregiving mother and the father do not share the same relationship to their child in care. She is still caregiving and doing so unremunerated. There is no legal term for what she is in law. The experience of the mother in *J.M.S.*, and the facts of her case, "are not subsumed within the traditional boundaries" of the law.¹⁰⁰⁶ Indeed, they are not subsumed by law at all, for its provisions do not anticipate mothers like her, which is the larger point being made here.

Respectfully, the majority decision reflects an ongoing problem for caregiving mothers, which is that facts (in this case caregiving and support related) must "fit" within legal boxes. The order for wardship issued several years previous to this hearing was in regards to *disability* care, although it had the trappings of a child protection case. Having been deployed, I argue that the protection myth caused the court to misapprehend *the nature* of the mother's relationship with the ward in state care. For example, Justice Meehan opined that "[e]xercising access to the child, no matter how laudable, is not having

¹⁰⁰⁶ Kimberlé Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics and Violence against Women of Colour" (1991) 43:6 Stanford Law Review 1241 at 1244.

custody and control of the child.”¹⁰⁰⁷ The mother’s actions to remain active in her disabled son’s life are framed as “good behaviour,” conduct that is to be praised, but that is clearly divorced from caregiving mothers’ rights to support.

In family and child welfare law, there are different support-of-child regimes. Where a child is made a ward of the state his or her support falls within the (public) purview of the province. Where a child’s parents are separated, and the child is legally “a child of the marriage,” child support is usually payable (privately) to the parent with whom the child is primarily resident.¹⁰⁰⁸ Although *J.M.S.* was heard towards the end of the era of SNAs in Ontario, it was not a SNA case, because, pursuant to those agreements, parents could retain custody of their disabled child, and that was not the situation in *J.M.S.* This case challenges us to consider the myths at play.

The *J.M.S.* court stated that in law there is an entitlement to support from either the state or the father, but there was no entitlement to support from both, which was what this mother and others like her, require.¹⁰⁰⁹ This case centred on the issue of in whose legal charge was the disabled child; he was held not to be in the charge of his parents.

The claim for child support in *J.M.S.* brought by the mother of a disabled crown ward, existed at the intersection of child welfare and family law.

This case lends itself to an application of Crenshaw’s¹⁰¹⁰ intersectional legal lens, although not in the same sense of the examples Crenshaw provides. Crenshaw examined the judicial treatment of the intersection of specific kinds of claims pursuant to Title VII cases under the American Federal *Civil Rights Act*.¹⁰¹¹ In so doing, she was able to demonstrate that the refusal of those adjudicating rights claims to recognize that black women experienced *combined* sex and race discrimination. In her analysis of such cases, Crenshaw showed that it was possible for courts to adjudicate cases where women were a special class and cases where black men were a special class, but that they were unable to recognize civil rights discrimination at the intersection of the two, where the plaintiffs were black women. She posited that the approach taken *vis-à-vis* the class of women was based on *white* women’s experiences and the class of Black litigants, redress was based on the experience of black *men*. She claimed that such an approach obscured the intersection where black women claimants were situated.¹⁰¹² Crenshaw’s theory

¹⁰⁰⁷ *J.M.S. supra* 15 at para 29.

¹⁰⁰⁸ This statement is a simplification and does not take into account alternate arrangements than the most typical one where the child lives with a child-support-receiving mother.

¹⁰⁰⁹ *Favrod, Ansell, and J.M.S.* all suggest that the state is ideologically at odds with shared care, contrary to what it stated in the preamble to the ODSP provisions.

¹⁰¹⁰ Kimberlé Crenshaw, “Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Anti-Discrimination Doctrine, Feminist Theory and Anti-Racist Politics” (1989) 140 U Chicago Leg Forum 139.

¹⁰¹¹ *Civil Rights Act* 1964, 42 USC § 2000e, et seq as amended (1982).

¹⁰¹² Crenshaw, *ibid* at 143.

brilliantly showed that a ‘one size’ fits all in the law (women, blacks) was itself vulnerable to racism and sexism and as a result certain women were left unprotected under the *Act*.

Although the circumstances of caregiving mothers and the courts they bring their claims to are different from American Title VII cases, I argue that there is likewise an invisible intersection with legal implications that need to be recognized so that caregiving mothers can recognize their right to support. This issue was illustrated well in *J.M.S.* where the *claim* for child support brought by the mother of a disabled crown ward resided at the intersection of two distinct areas of law and two distinct pieces of legislation, child welfare and family law. The issue on appeal was whether a parent who does not have custody or charge of the child is entitled to guideline child support.¹⁰¹³ In this case, the mother sought child support from the father, but he claimed his son was ineligible for it, because he was a ward of the state. What was learned in this case is that is the claim to support for a child, a disabled one, was simply unobtainable under the particular facts of the case. Neither family law nor child welfare law is set up to meet the support needs of mothers like the one in *J.M.S.* who continue to provide care.

Notably, Justice Molloy, in her dissenting judgement, stated that she did not agree that a child found to be in need of protection and care from a Children’s Aid Society is not necessarily also a child of the marriage pursuant to the *Divorce Act*. She stated that in situations such as the case at bar, courts must look “at the particular context” of the child in order to determine whether the child’s support-seeking parent can be seen as retaining her charge of the child, even though the child has been made a ward of the state. She opined that the reason for this was that wardship was based on need for treatment and care by reason of the child’s severe disability and not because of any child protection needs.¹⁰¹⁴ Madam Justice Molloy may not be technically correct based on prior understandings of the meaning of “charge,”¹⁰¹⁵ but she is thinking outside the box in opining that a contextual analysis was called for, and that such an analysis would lead to the very conclusion at which she arrived. One could say that the majority relied upon a legal fiction to adjudicate *J.M.S.*

Legal fictions also arise in the setting of child welfare legislation, which defines the child in need of protection. One protection finding a court may make is on the basis that the child has been

¹⁰¹³ *J.M.S.* *supra* note 15 at para 14

¹⁰¹⁴ She states in *J.M.S.*, *supra* note 15 at para 37, that “I also agree that the correct interpretation of the words ‘has not withdrawn from their charge’ in subsection 2(1)(a) of the *Divorce Act* does not import any requirement of an overt voluntary act on the child’s part in withdrawing from his parent’s charge. The fact that a child is no longer ‘in the charge’ of the parent seeking the support order is sufficient to take the child out of the definition of ‘child of the marriage’ in the *Divorce Act*. However, I do not agree with Justice Swinton that such an interpretation inevitably leads to the conclusion that a child who has been found in need of protection and is therefore in the care of a children’s aid society is necessarily not a ‘child of the marriage’ within the meaning of the *Divorce Act*.”

¹⁰¹⁵ The word “charge” is used in the *CFS* to refer to the individual with legal responsibility for and obligation of care for the child. A charge is a child committed to the care of someone, which may be the state or a private party.

abandoned.¹⁰¹⁶ In the setting of disability, the abandoning mother is a powerful myth, and indeed, it is counterfactual in child welfare law, where the abandoning mother is constructed in non-abandoning settings. It arises where severely disabled children require residential placements, while also having caring and highly committed mothers. The abandoning mother myth (and its accompanying legal practice) arose, I argue, in direct response to women violating the ableist and patriarchal norms set for caregiving mothers by privatizing neo-liberal administrations in the second half of the 1990s. Expected to provide long-term heavy care, largely alone, caregiving mothers of severely disabled children have since persistently demanded care supports from the state. In Ontario, the “support” offered to them has come in the form of a legal finding of child abandonment through child protection legislation. The myth of the need for state protection and its corollary, the myth of maternal abandonment, have great significance for disabled children and their caregiving mothers alike. It is one in which the state’s “contempt” for mothers who claim they can no longer provide care to their severely disabled child is made plain. Freire states that emergence into a state of critical consciousness brings about the discovery that the oppressors are contemptuous of the one emerging.¹⁰¹⁷ I suggest that the way in which mothers have been treated by provincial governments who used this avenue to provide care has played a role in furthering changes in how caregiving mothers view their circumstances.

Drawing again from the notion of critical consciousness, I suggest that a caregiving mother may leave what was formerly shared consciousness; that is to say, a structure of consciousness described by Olsen as comprising a ‘shared vision’ of the social universe as one that shapes the view of what relationships are natural and what reforms may be achieved.¹⁰¹⁸ The mother in this case was aware of the legislation, had problematized it in relation to her circumstances, and then rejected it.

In *The Children’s Aid Society of Halton v J.A.1 and J.A.2*, the mother moved into a different legal awareness of her circumstances.¹⁰¹⁹ In this case, the mother of two engineered her own disabled child’s apprehension, and then she engaged with the myth of protection in her court materials.¹⁰²⁰ She did so,

¹⁰¹⁶ A child is in need of protection pursuant to the *CFSA*, *supra* note 762 s 37 (2) (i), where “the child has been abandoned, the child’s parent has died or is unavailable to exercise his or her custodial rights over the child and has not made adequate provision for the child’s care and custody, or the child is in a residential placement and the parent refuses or is unable or unwilling to resume the child’s care and custody.”

¹⁰¹⁷ See Fritz, *supra* note ##.

¹⁰¹⁸ Olsen, *supra* note 134 at 1498

¹⁰¹⁹ *Children’s Aid Society of Halton v J.A.1 & J.A.2*, 2011 ONCJ 624 [J.A.1.]

¹⁰²⁰ Mothers across Ontario have “abandoned” their minor and age of majority children. While the legal circumstances are different where children are no longer minors, the fiction of abandonment is similar. On an additional note as to legal fictions and the rather “loose” application of concepts in this area of law, I note that part of s 37 (2)(i) of the *CFSA*, *supra* note 762, refers to the parent who is ‘unable’ to exercise her custodial rights. Presumably this refers to custodial obligations. The custodial domains in family law usually refer to providing nurture and support and decision making in religious upbringing, education and medical care. Where severely disabled children are concerned under the *CFSA* child protection scheme, the Minister seems to treating mothers as failing in one of the family law custodial domains, decision making around medical care. However, there is no

even though it appears she did not agree with the child welfare practice of requiring caregiving mothers to consent to a child protection finding in order to access care.

The facts of *J.A.I* are that both of the parties' children had been in the primary care of their mother from the date of separation. During 2009, the father had been exercising access to both of his children at a supervised access centre, on a family law court order issued on consent. In 2010, the child was "apprehended" by the regional children's aid society because the mother could not care for their disabled child, M.A., at which point the parents consented to undergo a custody and access evaluation.¹⁰²¹

The circumstances of the mother at the time of the staged (by the mother) apprehension are set out in the case as being in the setting of the deterioration of the child's behaviour, believed to have occurred with the end of his behavioural therapy and the start of a new program. The decision states the mother had funding for two respite workers "to assist" with treatment and with care of her child. At the time of the apprehension, the mother was working with one respite worker and with her own mother in caring for the child. In spite of having three other adults to assist with care, the evidence of the pediatrician¹⁰²² was that in the setting of behaviour becoming increasingly difficult to manage, the mother was exhausted, frequently breaking down in his office. The physician's evidence was that the care needs would not be solved with week or weekend respite, and that the family had exhausted all of its resources. He recommended placement, given the lack of adequate state supports.

The child (M.A) was "apprehended" after his mother brought him to a hospital emergency room and informed a physician there that she could no longer care for him, leaving him there so that child welfare authorities would be alerted. He was placed in a residential treatment program and a child protection application was brought against the parents. The affidavit the mother provided in response stated that the principal of the school, the IBI therapist, and the primary respite worker all supported the plan of care she put forward, which advocated for a residential placement. The mother's materials explained that the school board had consulted its autism expert and had repeatedly called the mother to collect the child from the school because of difficulties. The materials also set out that the grandmother, the mother herself and two respite workers had been caring for the child.

In the initial motion to apprehend, the Society agreed with the mother's position that the child be placed in a residential program for seven months as a ward of the Society. As the decision notes, on return of that motion, the Society had changed its position, seeking instead to place the child in temporary custodial care with the father, with the supervision both of the father's parents and subject to society

custodial domain that involves being a health care provider to ones very sick child. As such that reality remains unaddressed.

¹⁰²¹ The mother had called the child welfare agency and the intake worker noted the child yelling in the background. Her call was not returned for a week. The mother drove the child to a hospital where she told authorities she could not provide care. *J.A.I*, *supra* note 1019 at para 18.

¹⁰²² *Ibid* at para 13.

supervision¹⁰²³ The mother did not agree to this newly proposed plan of care. In the end, the court held that as the child's "primary caregiver was unable to care for him, even with the assistance of two primary respite workers, and at the time of the apprehension, the assistance of one full-time respite worker and her mother" and given that "professionals involved in M.A.'s care have recommended that he be placed in a permanent residential treatment home that will meet the special needs of a child with severe autism that is where he should be placed."¹⁰²⁴

A finding was made under s 37(2)(b)(i), which is Part III of the Ontario *CPSA* dealing with child protection. Subsection (i) is for a finding of abandonment. Demanding and reframing the nature of the support she sought, the mother brought attention to what she submitted was the mischaracterization of the reasons for the placement of her son into a residential facility. Her position in this matter is in the court record and was reflected in the decision. The Judge's Endorsement in this matter states:

In its protection application dated November 29, 2010, the Society seeks a finding that M.A. has been "abandoned" by his mother... It is not in dispute that M.A. was in the Respondent mother's care and charge at the time of the Society's apprehension of the child. *The Respondent mother does not agree that she has abandoned M.A., but rather that she was no longer able to care for him.*¹⁰²⁵

This mother had recently left a violent relationship, she had health problems, and she had a job that she needed in order to support herself as a sole-support mother with another child to care for. She was also in the stressful process of placing her child in residential care, and being forced to do so through a combined domestic and child welfare court proceeding. Yet, the legal finding of abandonment of a child, whom she was in the active process of supporting in a great many domains, troubled her enough to raise it in her Reply to the Child Protection Application served on her.

This mother makes it clear in her submissions that she was not abandoning her child. This is significant as she was asserting that the use of a legal fiction to describe her actions was unacceptable to her. It is also significant that the Judge included her perspective on this point in his decision and I argue that this inclusion was purposeful. This mother was an excellent copier who found herself in an untenable set of circumstances where her child required care she did not have the expertise or resources to obtain or provide. While I do not have her Reply, or her accompanying affidavit, the text of the decision suggests

¹⁰²³ *J.A.I.* supra note 1019 at para 21

¹⁰²⁴ *J.A.I.*, supra note 1019 at para 44, The child's disability is described thus in the Endorsement, relying on the father's Affidavit this time and it states that the child was severely autistic only able to communicate by pointing, using gestures and sounds and as having violent behavior.

¹⁰²⁵ *Ibid* at para 2. My emphasis.

that this mother, through her legal counsel, both problematized and resisted the myth of her alleged ‘abandonment’. Where Scorgie and Sobsey’s¹⁰²⁶ approach might label this mother “a bad cop,” the facts of the case indicate otherwise. Since she had developed the ability to discern the legal counterfactual that named the inability of four adults and a teacher to cope with the required level of care as ‘abandonment’, she was able to understand that her deep commitment to her child was being framed legally as just the opposite of that. She understood, however, that she had to be complicit in the legal fiction of her alleged abandonment in this policy setting, in order to gain access to services. She determined that it was in her child’s best interests for her to engage in this disturbing process.

This oppressive pathway to accessing state care (in the setting of a state that does not want to provide it) corresponds with Freire’s observation respecting duplicitous aspects of oppression. The abandoning mother forms part of an ideology, one that undergirds motherhood in general, but which is more pernicious towards mothers in its ableist manifestations. Failed, bad, and non-coping mothers abandon; coping, successful, and good mothers do not. In comparison, the abandoning state does not receive such a harsh condemnation. Where caregiving mothers are concerned, their competence and value appears to be constructed through binary opposites, with (bad) abandoners as one construction and exemplary mothers as the other. Both are oppressive, with maternal deprivation and maternal exploitation taking place respectively.

Having reviewed the myth of abandonment, I now turn to examine its counterpart, maternal exploitation.

Myths of Equality

I mention *McCrea v The Attorney General of Canada and The Canada Employment Insurance Commission*¹⁰²⁷ here because until the need was perceived by mothers to bring this lawsuit many of them may have seen themselves as “equal” to other federal employees. *McCrea* involves Canadian mothers who brought a class proceeding against the federal government in 2015 concerning state support (monetary benefits) to mothers with infants on care leave. This case has something important to say about how mothers involved in intensive caregiving are sidelined in support law having to do with medical disability. It also has information to share, which is that leave to care for children who have become “disabled” must be for children who are temporarily so.

I have addressed the literature about motherhood as an institution in earlier chapters and this literature should be borne in mind in the case of *McCrea*. This is because the facts of *McCrea* and how

¹⁰²⁶ See Scorgie & Sobsey, *supra* note 160 at 198.

¹⁰²⁷ *McCrea v Canada (AG)*, 2013 FC 1278 [*McCrea*]. *McCrea* settled in 2018. See Laurie Monsebraaten, “Ottawa Settles Class action with new moms” (11 September 2018) online: <
<https://www.thestar.com/news/canada/2018/09/11/ottawa-settles-ei-sickness-class-action-with-new-moms.html>

government has responded to them, underscore the point that the care mothers provide, and the support they need, continues to trouble law, including law put in place by government to provide support. *McCrea* is useful because it calls on us to consider mothers may not be able to care, for a variety of reasons. And law should be responsive to that.

The facts of *McCrea* are that mothers on maternity leave who became sick, some life-threateningly so, applied for Federal disability benefits, which were denied. The reason provided was that they were receiving maternity leave benefits.¹⁰²⁸ This disentitled them to sick leave benefits. The aim of the mothers was to certify a class action proceeding against the Canada Employment Insurance Commission. Although based on several claims, only one claim was certified and that was for negligent implementation of the Act in question. One aspect of the negligence they claimed took place was the pattern of denials of sickness claims by very ill mothers on maternity leave;¹⁰²⁹ this pattern of denials continues.¹⁰³⁰ Early on, the government settled with some employees in the dispute, and it removed a clause in the benefit scheme that was problematic.¹⁰³¹ This case has correspondence with some others cases I discuss in this thesis in that supports mothers who provide care continue to remain invisible in law.

McCrea had contributed to the EI program, had a baby, and received maternity leave payments. However, she became ill while on maternity leave, and applied for sick benefits, but her request was denied. She brought a claim arguing that the strict interpretation of the *Act*, which required that a sick benefit-recipient be available for work during coverage, was restrictive and that government was negligent in its refusal to allow the sick benefits to sick new mothers. She pointed out that sick pregnant

¹⁰²⁸ The appellant mother's action was for denial of sick benefits under the *Employment Insurance Act*, SC 1996 c 23 [EI], regarding parental benefits under EI when parents became ill. The claim alleges that the Canadian Employment Insurance Commission and Service Canada failed to properly implement the amendments, which resulted in individuals who were on parental leave being denied their claims for sickness benefits. The class claimed misfeasance of public office, negligent misstatement and unjust enrichment. The Federal Court certified the class proceeding for negligent implementation of the *Act*. The government appealed and that litigation has been ongoing. See the more recent decision, *McCrea v Canada (AG)*, 2016 FCA 285.

¹⁰²⁹ *McCrea v Canada (AG)*, 2015 FC 592, (Motion for Class Certification), online: <<http://www.cavalluzzo.com/docs/default-source/News-Items/order-and-reasons-%28c1327631xa0e3a%29.pdf?sfvrsn=0>> [*McCrea* (Class Certification)].

¹⁰³⁰ The motion for the class action for \$450 million in damages was heard in the Federal Court in 2015 and the plaintiff mothers succeeded.

¹⁰³¹ The impugned provision stated that disability benefits are available only to people who would otherwise be available for work. Being at home taking care of an infant was not "work". In 2013 the clause about being available for work was removed, but the rule preventing sick benefits for mothers on maternity leave remained in force. See Gloria Galloway, "Ottawa Spends \$1.3 Million Fighting Sick Moms' EI Disability Benefits Lawsuit", *The Globe and Mail* (30 January 2015) online: The Globe and Mail <<http://www.theglobeandmail.com/news/politics/ottawa-spends-13-million-to-prevent-sick-new-moms-from-collecting-ei/article22731091/>>.

workers could access the 15 weeks of sick leave followed by maternity leave under the legislation, but that statutes excluded new mothers with medical disabilities/illnesses.¹⁰³²

Some other problems arise as well. Since *McCrea* was certified as a class action, the federal government has passed the *Helping Families in Need Act*.¹⁰³³ This *Act* contains provisions based on compassionate grounds and critical illness, a positive addition in the area of support. In this regard, it offers a maximum of 52 weeks leave for care of a *critically* ill child. However, this is not the same thing as a provision concerning care for a *chronically* ill or severely disabled child.

A point made in the literature review (with reference to the work of Cheryl Gibson) is that critical care may be accommodated by society, but *chronic* care presents a problem. In this benefit scheme, the definition of *critically* ill child provided by government *excludes* a child who is always severely disabled. A critically ill child is defined as “a child who has a life-threatening illness or injury, that can include various acute phases of illness and for which continued parental care or support is required. This does not include a child with a chronic illness or condition that is their normal state of health. There must be a significant change from the child’s normal or baseline state of health at the time they are assessed by a specialist medical doctor.”¹⁰³⁴ This support policy to mothers sidesteps the issue of what happens when a worker gives birth to a severely disabled infant. If she had a critically ill baby, one wonders if she would have difficulty accessing the additional benefit. Either way it may not be easy to access support. Tellingly, the name of this *Act* is more evocative of charity than it is of maternal entitlement. In terms of federal government opposition to the caregiving mother’s negligence claims, Stephen Moreau, legal counsel to *McCrea*, has stated, “We are talking about individuals who were ill, sometimes quite seriously, while trying to take care of their children...It’s quite shocking.”¹⁰³⁵

McCrea (like the case of Cynthia Harris discussed elsewhere) offers an example of how working mothers’ state supports fail in the setting of severe illness or disability. It is an example that invites one to consider government’s rejection of the claims to support in the convergence of disability, mothers, infants and care.

¹⁰³² *McCrea* (Class Certification), *supra* note 1029 at para 5.

¹⁰³³ For example, since *McCrea* was certified as a class action the federal government has passed the *Helping Families in Need Act*. See Laurie Monsebraaten, “\$450 Million Lawsuit Filed Against Ottawa to Win EI Sickness benefits”, *The Star* (26 December 2012) online: https://www.thestar.com/news/canada/2012/01/19/450m_class_action_lawsuit_filed_against_ottawa_to_win_ei_sickness_benefits.html. *Helping Families in Need Act*, SC 2012, c 27.

¹⁰³⁴ “EI Benefits for Parents of Critically Ill Children – Overview”, (7 June 2016) Government of Canada, online: <https://www.canada.ca/en/services/benefits/ei/ei-critically-ill-children.html>.

¹⁰³⁵ Monsebraaten, *supra* note ##. Moreau is also legal counsel to two other mothers, whose surnames are Rougas and Kasbohm.

The Myth of Ordinary Mothers

A feature of oppressive structures is that they hide the very features that oppress. In the setting of mothers with severely disabled children, state policy hides extraordinary disability-related and medical care mothers of severely disabled children provide.¹⁰³⁶ It presents such maternally complex care as an extension of ordinary mothering. The responsibilities of extraordinary “mothering” set unreasonable expectations on mothers’ performance of complex care and set the bar unattainably high for mothers with severely disabled children, irrespective of circumstances. Making such structures visible is one aspect of mothers’ legal activism.

The myth of ordinariness arises in the workplace in the sense that the failure to properly accommodate caregiving assumes extremes of maternal extraordinariness. Many mothers and their advocates are conscious of the fact that women’s rights in the workplace have advanced such that childcare obligations must be accommodated as a matter of provincial and federal human rights law.¹⁰³⁷ Decision-makers are called upon to protect caregiving mothers from discrimination in this domain.¹⁰³⁸ The Ontario Human Rights Commission has published a manual with its policy and guidelines on discrimination due to family status. This publication provides an example of a working caregiving mother requiring accommodations in relation to her disabled child.¹⁰³⁹ Yet, in the setting of severe disability in childhood, the mechanisms of oppression mothers experience remain firmly in place.

¹⁰³⁶ Extraordinariness is a term used by Manhas and Mitchell to describe demands placed on mothers with children with complex health care needs once care is transferred to the home. Manhas & Mitchell, “Extremes, Uncertainty and Responsibility”, *supra* note 199.

¹⁰³⁷ See *Canada (AG) v Johnstone*, 2013 FC 113, where it was apparent that a mother’s obligations to her children were held to have been not accommodated. The court upheld that the protection from discrimination on the basis of family status included obligations to care for one’s children. The matter was heard at the Federal Court of Appeal, which largely reaffirmed the trial court decision. *Canada (AG) v Johnstone*, 2014 FCA 110 [*Johnstone*].

¹⁰³⁸ This call has gone out for mothers generally. In the recent *High Stakes* report, produced by West Coast LEAF stated to be the culmination of their Right to Child Care Project, it was found through research that relied upon mother’s affidavit evidence, that weaknesses in child care services in British Columbia violate the human rights of women and children, and in a variety of ways. West Coast LEAF argues that that province has a responsibility to end these human rights violations. See Milne, *supra* note 312 at 28 where one affidavit provided that “The impacts of child care on the human rights of women and children under the heading “Caregiving Leads to Financial Crisis” the High Stakes Report states that “For women who work precarious jobs, even a temporary lack of child care services can have significant financial consequences. One project participant reported that her daughter could not attend child care for three months because she was wait-listed for disability-related supports. During this three-month period, the mother’s income declined drastically because she reduced her employment availability to provide unpaid care. She survived only because her low-rent apartment allowed her to cover housing costs with her daughter’s monthly child benefits and child support.”

¹⁰³⁹ Ontario Human Rights Commission, *Policy and Guidelines on Discrimination Because of Family Status*, Toronto: OHRC, (2007) online: OHRC <http://www.ohrc.on.ca/sites/default/files/attachments/Policy_and_guidelines_on_discrimination_because_of_family_status.pdf> [OHRC, “Policy and Guidelines”], provides an example of an accommodation required of an employer for the parent of a disabled child, using the mother as the parent to provide the example. The example in the code deals directly with the issue of work place “absenteeism” in respect of a lone mother with a disabled child.

This is evident in Cindy Moore's case, *Siemens Milltronics Process Instruments Inc v Employees Association of Milltronics*,¹⁰⁴⁰ as one exposing the power of the myth of maternal extraordinariness and tied to that, the myth of the failed mother.¹⁰⁴¹ In her case, societal myths proved too strong to overcome the workplace guidelines pertaining to mothers with severely disabled children, even though the right of caregiving mothers to accommodations in the work place is included in the Ontario Human Rights Commission policy manual. These guidelines and the mother's own litigation materials ought to have together persuaded the Arbitrator that Ms. Moore ought to have been accommodated, but she was not. The Arbitration decision solidified Moore's inability to realize her legal right to support.

Turning to the facts of this case, two claims were brought by Moore in *Siemens Milltronics*, and heard in arbitration. Moore alleged that her employer had breached the Collective Agreement and the *Human Rights Code* when it refused to pay her for days missed while caring for her severely disabled daughter. Her human rights complaint was for discrimination on the basis of family status.¹⁰⁴² The company's position was that because Moore had failed to work the regular, scheduled days preceding holidays, and because the reason for her absences (emergency child disability care) was unsatisfactory, she was not entitled to be paid for those days.

By way of explanation, Moore submitted that her husband had left that year and she was a sole-support parent. She stated that she had two daughters living with her, a 17 year-old in high school and another daughter whose age is not provided, but who is noted to have severe medical disabilities. This daughter attended a school full-time in what is described as a "special program". Moore stated that she

The manual was written in 2007, while *Siemens Milltronics*, *infra* note 1040, was decided in 2012. This suggests there remains a gap between what the manual provides and what happens in litigation.

¹⁰⁴⁰ *Siemens Milltronics Process Instruments Inc v Employees Association of Milltronics*, 2012 CanLII 67542 (ON LA) [*Siemens Milltronics*].

¹⁰⁴¹ Cindy Moore failed as a mother and as a worker because she could not meet the extraordinary and, I argue, impossible demands placed upon her in the setting of weak state support. Manhas and Mitchell describe expectations placed on mother's caring for children with complex health care needs as expectations of extraordinariness. See Manhas & Mitchell, "Extremes, Uncertainty and Responsibility", *supra* note 199.

¹⁰⁴² See the *Human Rights Code*, RSO 1990, c H19, s 5(1). American mothers have likewise brought this issue to the courts. The ADA for example may be used by working caregiving mothers. See *Washington v Illinois Department of Revenue*, 420 F 3d 658 662 (7th Cir 2005). From 1984-2000 Chrissie Washington worked from 7 a.m.-3 p.m., hours that permitted her care for her child who had Down Syndrome. Then, she was promoted, and some of her duties were changed. She complained believing this was racially motivated. Then her work hours were changed to 9-5 in another position and she was told to reapply for flexible scheduling. She used her sick and vacation time from 3-5 to provide care to her child, but that option eventually ran out. She brought forward legal complaints. She contends in this suit under Title VII of the *Civil Rights Act of 1964*, Pub L No 88-352, 78 Stat 241, that the agency moved her to a 9-to-5 schedule in retaliation for her earlier charge of discrimination. The parties consented to a magistrate hearing their dispute. The magistrate ruled that Washington could not show adverse employment action, because although her work hours had been changed, the duties and salary were the same. However, on appeal to the circuit court, it was held that employers may not exploit workers' special vulnerability. The court held that "At this stage of the litigation a court must indulge all reasonable inferences in Washington's favour", *ibid* at the last (unnumbered) para, the district court's judgement below was reversed, and the case was remanded for trial, i.e., it was returned to the magistrate. The term special vulnerability *à propos*.

engaged a personal support worker (PSW) provided by her local Community Care Access Centre (CCAC) who attended every weekday morning Monday through Friday for 1.5 hours to assist her daughter in getting to school. After school, a different PSW was employed privately by Moore, and paid for with external funding she received for her daughter from the province. When this PSW was not available to work (the evidence showed she also worked at a nursing home and therefore had to juggle schedules), then Moore's own mother provided the care. Moore's 17-year-old daughter also provided care. In short, five women provided care to the disabled girl. The father did not provide care, nor had he been involved with his disabled daughter since he left the family.

Turning to the workplace, Moore was a long-time employee who had worked for the company for twenty years. She missed work because, according to her evidence, the school had called her December 22, 2011 to advise her that her disabled daughter was vomiting mucus and blood. Moore submitted that these signs signaled that her daughter needed heightened care to avoid hospitalization. On December 22, Moore asked both her mother and the PSW to care for her daughter, but neither one was available. She advised her employer of this situation in advance of her missed shifts, making calls to her workplace, where HR was informed. Moore cared for her sick disabled daughter including on December 24th. The business was closed for holidays from December 24 to January 2. In response to her missed days, the company did not pay Moore for December 25 and 26, 2011 and January 1, 2012 as a result of her having missed days of work during the vacation period. In the decision, it is noted that Moore had been absent 19% of the year rather than the 14% of the time allowed in the collective agreement. The decision states that the company was understaffed during the holiday season due to employees taking pre-approved vacation leave. This was found by the adjudicator to be an "important consideration with respect to the company exercising its discretion to accept additional reasons for employees to be absent on qualifying days."¹⁰⁴³

Arbitrator Stout, having jurisdiction over the human rights claim as well, reviewed what he referred to as new and evolving case law on family status and concluded: "accepting the proposition that any employer action, which has a negative impact on a family or parental obligation, is *prima facie* discriminatory is untenable." He commented that attendance at work interferes with family responsibilities, but that "requiring work in exchange for compensation is a reasonable and *bona fide* requirement."¹⁰⁴⁴ This statement may be vaguely sarcastic, but it also ignored that Moore was working at home providing complex care to her ill disabled daughter without compensation, a feature that on the facts of this case, placed her livelihood in jeopardy.

¹⁰⁴³ *Siemens Milltronics*, *supra* note 1040 at para 47.

¹⁰⁴⁴ *Ibid*, para 64.

Mr. Stout's next opinion was that it is not the mother who was ill, but rather her disabled daughter, stating the mother was medically able to attend work, but did not do so because she did not have child care. He concluded that the reason for the mother's absence was not linked to her inability to work, but due to her inability to obtain care for her disabled child. He stated the mother had "some control" over finding care for her disabled daughter, but added, "Unfortunately, no one was available..." More importantly, he states, she had already exhausted her leave entitlements, including those of emergency leave.¹⁰⁴⁵ The result was that this arbitrator found there was no discrimination in response to her allegations that the company breached the collective agreement and the allegation that the company breached the *Ontario Human Rights Code* family status provision.

The Moore case presents a number of problems. One is that the arbitrator contradicts himself in his reasoning. The fact that Moore was vulnerable to having no childcare meant that she had no control over arranging her affairs to obtain assistance in providing for her disabled daughter, at least on these occasions. He further stated that he saw Moore was in a difficult situation as a single mother with a severely disabled child, and was sympathetic "with *her* predicament" (author emphasis). Another is the normative opinion rendered by the Arbitrator. He stated that all children become foreseeably sick and that the difficult choice faced by Moore *was no different* than those that other parents face where there is a conflict between work and family obligations, adding "That is why parents must plan for such situations and why emergency leave provisions exist."¹⁰⁴⁶ The arbitrator was focused on her leave entitlements, and could not envisage her as entitled beyond them. The comment made that the attendance policy of the company was "important" around the holidays with respect to the company exercising its discretion is an interesting one in light of the fact that the company chose to do so in the direction of punishing the mother of a child with a severe disability, by withholding pay.

The issue of what is the best approach for adjudicators to take in family status cases was addressed in an Ontario Bar Association employment law publication subsequent to the *Siemen's Milltronics* decision. The author of it states that the test seen to be most suitable is whether there has been serious interference with a substantial parent/child obligation such that that protection under the provisions is engaged. There must be a "substantial obligation" with respect to the care requirement.¹⁰⁴⁷ An important issue that remains unaddressed however is whether health care for a severely disabled child will fall easily under what the author calls an amalgamated approach. In such an approach, protections under family status are engaged where a 'substantial obligation' must be in the nature of a care

¹⁰⁴⁵ *Ibid* at para 69.

¹⁰⁴⁶ *Ibid* at para 78.

¹⁰⁴⁷ Adrian Ishak "Family Status Accommodation in Ontario – Taking the Middle Road" (Toronto: Labour and Employment Law Section, Ontario Bar Association, 2013) online: <http://www.oba.org/en/pdf/sec_news_lab_mar13_fam_ish.pdf> at 3.

requirement, and not the employee's preference on how such care should be provided.¹⁰⁴⁸ Arbitrator Stout did not appreciate this distinction, and he is not alone. Moreover, where a non-disabled child vomiting mucus and blood at school is framed in the workplace as an excusable parenting emergency, for *Moore* and others like her, it is a common concern.

In *Siemens Milltronics*, the arbitrator sympathized with the employer, "read in" Moore's circumstances as comprising undue hardship to the employer and therefore beyond the extent to which accommodations to a parent legally must be made. The implication to be drawn is that Moore failed to manage her circumstances well enough, and the message that this case sends is that employers can punish mothers with severely disabled children who miss work because of a risk of a child's hospitalization and/or lack of disability care. In fact, Moore's daughter has cerebral palsy and hypomyelination, the latter described in the case as akin to Multiple Sclerosis. This care situation is far from what other parents typically plan for in relation to their work. Thus, once again, one can see the challenges posed by the myth of extraordinariness (other mothers do it) and the myth of the failed mother (she planned poorly) applied in this decision to a caregiving mother trying to realize her legal right to workplace support.

Siemens Milltronics is not that different than the case involving Cynthia Harris, which I discuss in detail elsewhere.¹⁰⁴⁹ Briefly, *Harris*, a newly disabled mother with a severely disabled son, found herself outside the recency requirement of the federal disability benefit scheme by virtue of having had to care for her son longer than anticipated. She was unable to satisfactorily show that she had been discriminated against in the recency requirements as they were applied to her, a situation Hansen and Turnbull¹⁰⁵⁰ describe as adjudicators just not "getting it" where motherhood and disability intersect.¹⁰⁵¹ This "not getting it" can make caregiving mothers' lives impossible, as the next example reveals.

In Chapters Three and Four I referred to *maternally* complex care and the requirement placed on caregiving mothers to perform *extraordinariness* and later I discuss the myth of the extraordinary mother. Joyce Dassonville litigated for additional provincial disability support in *Dassonville-Trudel (Guardian ad litem) v Halifax Regional School Board* litigation.¹⁰⁵² I suggest that Dassonville emerged into a state of

¹⁰⁴⁸ *Ibid.*

¹⁰⁴⁹ *Harris v Canada (Minister of Human Resources and Skills Development)*, 2009 FCA 22, 4 FCR 330 [*Harris*].

¹⁰⁵⁰ Hansen & Turnbull, *supra* note 249. The SCC refused leave to appeal, *Harris v Canada (Minister of Human Resources and Skills Development)*, 2009 FCA 22, 4 FCR 330, leave to appeal to SCC refused, 33091, (9 July 2009).

¹⁰⁵¹ Again, see *Johnstone*, *supra* note 1037, where it was apparent that mother's obligations to children were held to have been not accommodated.

¹⁰⁵² *Dassonville-Trudel (Guardian ad litem) v Halifax Regional School Board*, 2004 NSCA 82, 50 RFL (5th) 311 [*Dassonville-Trudel*]. Remarkably, Joyce Dassonville also brought claims in British Columbia for *Charter* rights infringements and also for judicial review of government decisions affecting her and her daughter's support. Information obtained through email communication with Joyce Dassonville August 4, 2016. Dassonville provides an example of a litigating caregiving mother with high level of awareness of injustices in the area of disability supports to mothers.

heightened awareness when she subsequently commenced a proceeding for judicial review in the Nova Scotia Supreme Court when she recognized that the way the government was dealing with her need of support was unreasonable. The facts of her case are that she had three children: two with disabilities, with her daughter, Dominique, being severely disabled. Dassonville initially applied for funding in 1998 when Dominique was three years-old. At that time, she was advised by the program-administrator that her income as a lawyer disqualified her from receiving such benefits. In 2000, Dassonville left her law practice when Dominique was five years old, which is when non-disabled children start kindergarten. When Dassonville left her career to provide care, she became eligible for provincial funding, to be facilitated through a SNA with the Nova Scotia government. This is because the agreement was subjected to means testing and guidelines for allocation of funds. In June 2000 Dassonville was awarded \$300 per month for respite care and diapers. Dassonville believed that the support she received from the Ministry was insufficient. She thus in July 2000 she requested additional funds, and itemized for the department her daughter's annual needs. These needs included a speech pathology report (\$4,000), respite care (\$47,000), travel and accommodation expenses to attend autism information events (\$3,600), modification to the home to ensure the daughter's safety (\$6,250), additional money for her special diet, and so on.¹⁰⁵³ Dassonville claimed she needed \$71,000 a year for the itemized respite care alone.¹⁰⁵⁴ In response to her itemized request, in August 2000, her funding under her agreement was raised to \$600.¹⁰⁵⁵ The case does not opine on what that \$600 was intended to cover. That is roughly one-eighth of the cost of the speech pathology report, which is a medical report. It is obvious that this allocation is not a "sharing" of the costs of complex care between a mother and the province. The discrepancy in these numbers provides evidence of the struggle respecting needs interpretation within the domain of disability that takes place between support-seeking mothers and the state.¹⁰⁵⁶

Dassonville's application for increased respite care was denied. Disagreeing with that determination, she appealed internally through the Ministerial Appeal Panel, but the denial of an increase was upheld. She sought writs of certiorari and mandamus respecting the process involved in the denial of her application for increased levels of funding by the ministry.¹⁰⁵⁷ She *knew* that the government was not providing her with something to which she believed she was entitled.

¹⁰⁵³ *Dassonville-Trudel*, *supra* note 1052 at para 43 [2004 decision]

¹⁰⁵⁴ Manhas, "Sufficiency of Home-Care", *supra* note 182 at 289.

¹⁰⁵⁵ *Dassonville-Trudel*, *supra* note 1052 at para 43-44

¹⁰⁵⁶ See Fraser, "Talking about Needs", *supra* note 4 at 295.

¹⁰⁵⁷ What makes the *Dassonville-Trudel* case additionally interesting is that in the spring of 2001, the Nova Scotia government suggested Dominique be placed in state care ("in a situation outside the family home", *Dassonville-Trudel*, *supra* note 1052 at para 72). The mother did not agree. Three months after that, the mother referred to herself as needing state care, with the assertion that if funding could not be accessed for her daughter, then the government should find Dominique to be a child in need of protection pursuant to the Nova Scotia, *CFSA*, *supra* note 851, s 22. A week later, the government department replied to her request, however she stated she did not need

On review, the court found the bureaucratic decision-maker with carriage of her file had incorrectly treated the policy guidelines as representing a barrier to a higher award of support, when in fact they did not.¹⁰⁵⁸ Indeed, the court held that there had been an “irrational application” of the guidelines by government.¹⁰⁵⁹

Notably, Dassonville had added constitutional claims to her application for judicial review, alleging that the province’s refusal to provide her with adequate funding for Dominique was contrary to her both her and her daughter’s rights under the *Charter of Rights and Freedoms*.¹⁰⁶⁰ In the judicial review proceeding, the appellant mother and child were awarded costs and the decision was quashed and sent back to the government for a redetermination.

Respecting Dassonville’s inability to practice law when confronted with weak state support, Kiran Manhas comments: “Ms. Dassonville continued to have to forgo a skilled career outside the home to facilitate the family’s eligibility.”¹⁰⁶¹ Manhas also observes that the government’s calculations of entitlements in *Dassonville* represent a “gendered devaluation of care,” which was visible in that province’s responses to this mother’s urgent requests for support.¹⁰⁶² It also reflects a devaluing of her need to earn money to ensure her future economic security. In fact, Joyce Dassonville was an extraordinary and highly competent lawyer, managing to engage in protracted litigation on her own against government lawyers, while caring for three children, two of whom were disabled.¹⁰⁶³ She was not in possession, however, of the ability to do what the province expected of her, which was to fund and care for Dominique on her own.

the state to take over the care of Dominique, but rather she had made the referral “out of desperation.” See Manhas, “Sufficiency of Home-Care”, *supra* note 182. Then the mother asked for a statement of the government’s rationale would be respecting initiating child protection proceedings for Dominique. The latter made good sense in my view from an evidentiary perspective. The government had already stated there were concerns as to the mother’s well-being and had itself suggested state care. The government, therefore, was fully cognizant of the harm being experienced by the mother in her grossly under-supported circumstances. Manhas comments on the mothers’ flip-flopping on state care versus maternal care, as something that seemed to reduce the mothers’ credibility in the eyes of the court, underscoring “the wretchedness” of her “almost incomprehensible” situation. *Ibid*, at 291.

¹⁰⁵⁸ See Pottie & Sossin, *supra* note 498 at 153.

¹⁰⁵⁹ *Dassonville-Trudel*, *supra* note 1052 at para 38.

¹⁰⁶⁰ *Ibid*, at paras 6, 23. She claimed sections 7, 12 and 15 were infringed. The 2004 decision states “She sought, as well, a finding that certain decisions of the Minister of Community Services, the Department of Education and the Halifax Regional School Board were contrary to ss 7, 12 and 15 of the Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, being Schedule B to the Canada Act, 1982 (U.K.), 1982, c. 11.” *Ibid* at para 6. The action was brought by her and by her daughter, with the mother acting as guardian ad litem for Dominique.

¹⁰⁶¹ Manhas, “Sufficiency of Home-Care”, *supra* note 182 at 291.

¹⁰⁶² *Ibid*.

¹⁰⁶³ For example, the 2002 decision of Justice Coughlan, *Dassonville-Trudel (Guardian ad litem) v Halifax Regional School Board*, 2002 NSSC 110, 205 NSR (2d) 881 [*Dassonville-Trudel* (2002)], shows counsel listed as: Joyce L. Dassonville, for the applicants, Catherine J. Lunn, for the Minister of Community Services of Nova Scotia, The Department of Community Services, The Minister of Education of Nova Scotia and the Department of Education. Lyle Ian Sutherland, for the Halifax Regional School Board.

Dassonville, and others bringing claims like hers, may be challenging newer myths, as well as established ones. A discourse that emanates from disability rights about community living is that it not as expensive as the alternatives. Certainly, community living arrangements may not be as expensive *to the state* as are the known alternatives, but this is not true for caregiving mothers. The high dollar amounts for disability-related care needs tallied by mothers in their legal submissions are disturbing to those advocates aware that the government is already reluctant to support persons with disabilities. Those advocates who downplay the real costs of disability care at home seem to want parents to assume that responsibility.¹⁰⁶⁴ However, I argue that approach demonstrates reliance on a middle-class, male breadwinner, heterosexual family model, and I do so without suggesting that it is suitable for caregiving mothers even in that ostensibly more stable family context to be responsibilized as they are. It is less messy for the disability rights community, already struggling for meagre supports amid dwindling interest, to remain silent respecting the state's approach to caregiving mothers, which is to expect that mothers will do the heavy lifting *and* bear the economic burdens of care in respect of their/our severely disabled children.¹⁰⁶⁵ In shying away from the fact that the heavy lifting I refer to may include forms of extremely costly care that, when performed in the home, to quote Laura Rosen-Cohen, "crush" caregiving mothers,¹⁰⁶⁶ government and advocates *do not* advance the rights of children with severe disabilities.¹⁰⁶⁷

It is significant that Dassonville did not agree with the only other option the state presented to her, which was to place Dominique in state care.¹⁰⁶⁸ It is *the mother* in this case who shielded her child from the state's suggestion that Dominique give up her right to live in a family environment, and she did so at great personal and professional cost to herself.¹⁰⁶⁹ Thus, mothers are put in the position of having to choose between their own support and the broader support needs of their disabled children, and in so doing, may relinquish their right to support themselves.

¹⁰⁶⁴ See *Nieberg*, *supra* note 785. Diane Wintermute at ARCH Disability Law Centre acted for Clough and Nieberg.

¹⁰⁶⁵ As stated elsewhere there are those within that community who are socially conservative, and who believe things are as they should be, with mothers providing full time care to disabled children in the home.

¹⁰⁶⁶ Laura Rosen Cohen, "Crushing the Caregivers", *The National Post* (5 May 2014) online: The National Post <<http://news.nationalpost.com/full-comment/laura-rosen-cohen-crushing-the-caregivers>>. Dawn Roper stated that "Families need flexible individualized funding, but instead the government relies on the nearest woman who loves the person with a disability to throw away everything in her effort to provide care without adequate support. There could perhaps be an Ombudsman's report about that." Dawn Roper, "Families need flexible, individualized funding..." (24 September 2016), posted on *Ontario Family Alliance* (Closed Facebook Group), reproduced here with permission.

¹⁰⁶⁷ As Carnevale et al point out, severely disabled children are disturbed that their care should exert physical burdens on their mothers, whom they love and care about. Carnevale provides the example of a disabled child asking her mother if she would prefer that she were dead rather than having to carry her assistive technology. Carnevale et al, "Daily Living", *supra* note 360 at e57.

¹⁰⁶⁸ She is reported to have considered it briefly at one point over the course of this case. See Manhas, "Sufficiency of Home-Care", *supra* note 182 at 291.

¹⁰⁶⁹ See for example Victoria Weisz & Alan J. Tomkins, "The Right to a Family Environment for Children with Disabilities" (1996) 51:12 *American Psychologist* 1239.

Dassonville sought to uncover the legal “truth” as to her purported ineligibility for a greater award of support for Dominique. She had an appreciation that her rights under the *Charter* were infringed by government conduct in her case.¹⁰⁷⁰ The reality, regardless of rationale, is that state gatekeepers try to deny higher levels of support.¹⁰⁷¹ Thus the so-called *irrational* feature of government decision-making noted by the appellate court in this case was not entirely irrational. It was, however, unjust. Part of the reason why this policy approach may not appear unjust or harsh to many is because it is presumed all along that mothers will take on the burden of care, in the way Bombeck celebrates, as a form of sacrifice (charity). Bombeck’s writing about the qualities of mothers with disabled children described earlier reads like a fable in fact.¹⁰⁷² Fables are fictional stories, but caregiving mothers who require support live in the real world.

Myth of Political Leadership

In many cases where courts find they ought not to provide a remedy for what is determined to be decision-making of the executive branch (policy-making), litigants are reminded that the legislature is the place where a mother’s focus should be directed. Experiencing Canada differently, mothers with severely disabled children have made complaints to their MPPs and their Ombuds about the many problems with which they live.¹⁰⁷³ Dissatisfied with their inability to acquire appropriate levels of service or funding through public policy, mothers have taken political avenues to bring about change. An example of this was seen in the efforts of Miriam Edelson.

Edelson was a union representative for the Public Service Alliance of Canada, the union representing federal public service workers.¹⁰⁷⁴ She used her skills to protest government cutbacks and

¹⁰⁷⁰ Joyce Dassonville’s *Charter* claim, like those of Nicole and Jamie Courtney, discussed in the next chapter, did not survive. In 2002, in *Dassonville-Trudel* (2002), *supra* note 1052 at paras 18-22, Justice Coughlan, held in chambers that a trial would be required to hear the relevant evidence and moreover that an application was not the correct procedure in which to decide the issues. The judge commented that many facts and much evidence were in dispute. He referred to the Rules of Civil Procedure and found that an Action would be the appropriate course of action for Dassonville. Dassonville states in an email to me from 4 August 2016, that the two *Charter* cases she brought, in Nova Scotia and in British Columbia were dropped because of the *Auton* (2004) case, which proceeded on similar issues, and which she informed me effectively acted as *stare decisis* on findings in lower courts. The constitutionality of support law as applied to these two mothers was called into question by them, but Ontario and Nova Scotia, and later British Columbia, halted further legal inquiries on various bases, into whether caregiving mothers and their disabled children’s *Charter* rights to support had been infringed. The doctrine of *stare decisis* has previously played a role blocking mothers from advancing their rights to support. This was also seen in the litigation brought by the 5 mothers with disabled children in *Sagharian v Ontario (Education)*, 2008 ONCA 411 [*Sagharian*].

¹⁰⁷¹ Different stories support this rationale. One is accountability to the taxpayer. Joyce Dassonville was a taxpayer. The Pekruls, in British Columbia, used the tax payor rhetoric to their advantage when they asked why their taxes could not be used to support severely disabled children in that province. See Tomlinson, *supra* note 201.

¹⁰⁷² Bombeck, *supra* at note 560.

¹⁰⁷³ Some have written letters to Prime Ministers and Presidents. See Jane Racca’s letter at Appendix I.

¹⁰⁷⁴ Miriam Edelson, *My Journey with Jake: A Memoir of Parenting and Disability*, 4th ed (Toronto: Between the Lines Press, 2000) at 12.

closures respecting services for disabled children in the mid-1990s. According to Edelson, she did so as a matter of justice.¹⁰⁷⁵ She states she was assured by government that adequacy of community services was an important consideration in decisions respecting closures.¹⁰⁷⁶

Edelson queried whether it was best to lobby the then Minister of the MCSS, Tony Silipo, or the NDP Caucus. She stated at one point that “fighting for our kid’s rights to services is a way of life.”¹⁰⁷⁷ Released from what Freire calls shared consciousness, one myth Edelson appears to have recognized is that of purported state largesse. She chose to go public, by contacting her member of parliament to support her in having the Toronto Star publish government plans to cut back funding of supports to disabled children and youth. She also attended the provincial legislature. When former NDP leader, Bob Rae, put questions about disability supports to (then) Conservative Cabinet Minister, Dave Tsubouchi, and he would not answer them directly, Edelson stood up in the gallery and shouted “You’re going to kill my child!” and was subsequently removed from the legislature by a security personnel.¹⁰⁷⁸

Edelson’s actions were reminiscent of those of the suffragettes who preceded her, who likewise sought to politicize what the state sought to keep in the domestic sphere, where the scope of women’s legal interests could be better constrained.

My purpose in summarizing mothers’ past claims is to convey the breadth of maternal litigation for support, as well as to underscore the point that the problem is political in origin and must be political in its resolution. Moreover, the law can be part of the solution. Issues arise in areas of private and public support and in a mixture of the two, in the areas of healthcare, funding, placements, respite, and other areas. This summary is not exhaustive. Mothers have asserted the right to: a fair procedure;¹⁰⁷⁹ support and review of a decision;¹⁰⁸⁰ accountability in the provision of nursing care and reimbursement for payment for private home nursing care;¹⁰⁸¹ a shared care agreement with the state;¹⁰⁸² no discrimination in employment based on Family Status;¹⁰⁸³ no denial of a disability benefit as a result of caring for a child with a disability;¹⁰⁸⁴ entitlement to a tax deduction or tax credit;¹⁰⁸⁵ insurance of an existing obligation on

¹⁰⁷⁵ In her advocacy to prevent the closure of Thisteltown Regional Centre for example, she endeavoured to make clear to government that “residential care and increased service options in the community are not mutually exclusive...” *Ibid* at 132.

¹⁰⁷⁶ *Ibid*.

¹⁰⁷⁷ *Ibid*.

¹⁰⁷⁸ *Ibid* at 144.

¹⁰⁷⁹ See Nieberg, *supra* note 785.

¹⁰⁸⁰ See *E.M.*, *supra* note 577; and *Dassonville-Trudel*, *supra* note 1052.

¹⁰⁸¹ See *LS*, *supra* note 359.

¹⁰⁸² See *A.L.* (2006), *supra* note 207.

¹⁰⁸³ See *Siemens Milltronics*, *supra* note 1040.

¹⁰⁸⁴ See *Harris*, *supra* note 1399.

¹⁰⁸⁵ See *Henschel*, *supra* note 915; and *Newfoundland & Labrador v Sparkes*, 2004 NLSCTD 16, 234 Nfld & PEIR 94 [*Sparkes*].

the state to support their disabled child will be in existence in the future.¹⁰⁸⁶ In pursuit of their rights, mothers have sued the state when promised existing support is not available in the future;¹⁰⁸⁷ sued for increased levels of and to reinstate former levels of funding for respite care;¹⁰⁸⁸ refuted a finding of abandonment;¹⁰⁸⁹ sued for a higher quantum of spousal support in the setting of mothering a disabled child;¹⁰⁹⁰ sued for spousal support while also working full-time and able to self-support when caring for a disabled child;¹⁰⁹¹ sued for spousal support as a result of being the sole caregiver to a disabled child;¹⁰⁹² sued the estate of a deceased mother to defend against the claim of a father who sought not to have to pay extraordinary expenses as disabled child support;¹⁰⁹³ sued for entitlement to receive both adult child support and state income supports simultaneously;¹⁰⁹⁴ sued for an entitlement to receive child support for a disabled child who is also a Crown ward;¹⁰⁹⁵ sued to have a court prevent government from clawing back private avenues of support when also in receipt of state support;¹⁰⁹⁶ and sued for never married mothers' ability to make the same claim for adult disabled child support as do married and divorced mothers.¹⁰⁹⁷ I note that not all of these legal actions were of the same ilk. Some were made pursuant to statutes and some were not. Sometimes claims were properly brought or defended under the statutory support provision, while other times it was a case of the mother trying to make her facts fit the legal provisions for support. Other claims challenged statutory support provisions that excluded certain caregiving mothers. In other of the examples cited above, rights-claims were made where mothers perceived a support right was denied them, but was accorded to others as being unjust. Again, at times they struggled to make their facts fit the provisions in question. This accords with what was described in the introduction, which is that mothers with severely disabled children seek support via rights available under statutes, benefits and those they believe ought to be accounted for in law, but are not.

The presence of such diverse litigation points to oppressive structures, which are set up to discourage caregiving mothers from fighting for any support they need beyond the meagre quantum the state *may* discretionarily provide under uniformly oppressive policy regimes. These cases highlight the point that even when they are eligible for support, mothers may be denied it. In such cases, mothers battle for support one woman at a time.

¹⁰⁸⁶ See *Krangle*, *supra* note 765; and *King v Sutherland*, 2004 CanLII 35094 (ON SC) [*King*, 2004].

¹⁰⁸⁷ See *King v Sutherland*, 2005 CanLII 6377 (ON SC) [*King*, 2005].

¹⁰⁸⁸ See *Self-Represented*, *supra* note 929.

¹⁰⁸⁹ See *J.A.I.*, *supra* note 1019.

¹⁰⁹⁰ See *Caldwell v Caldwell*, 2013 ABCA 268 [*Caldwell*]; *Jans v Jans*, 2013 ABPC 199 [*Jans*].

¹⁰⁹¹ See *A.L.Y. v L.M.Y.*, 2001 ABQB 311, 294 AR 274 [*A.L.Y.*].

¹⁰⁹² See *Jans*, *supra* note 1090.

¹⁰⁹³ See *McAdam Estate v McAdam* (2006), 27 RFL (6th) 173, 146 ACWS (3d) 106 [*McAdam* cited to RFL].

¹⁰⁹⁴ See *J.R.B.*, *supra* note 936.

¹⁰⁹⁵ See *J.M.S.*, *supra* note 15.

¹⁰⁹⁶ See *Ansell*, *supra* note 964; and *Favrod*, *supra* note 958.

¹⁰⁹⁷ See *Vivian*, *supra* note 997.

It has been pointed out that “individual gain does not change the structure of the system itself, nor underlying attitudes...”¹⁰⁹⁸ and as such, these “wins” have limited value. The reality is that the social and legal expectations placed on mothers to provide a range of health care services, disability support, and other forms of care to sick or disabled children, no matter how onerous or costly, cannot be changed one legal dispute at a time.

Although on the surface it may appear that the main thrust of cases brought across domains in public law has to do with a range of issues, what is at the heart of them is the degree to which caregiving mothers have been responsabilized for care by the state. This is particularly challenging when another prevailing myth is that the Canadian welfare state offers more than sufficient to support those in need of it. These cases also give lie to the presentation of the benevolent state, a powerful myth exposed in the litigation of mothers with disabled children as untrue. This myth requires that mothers disprove something that is not the case. In the next section, I address the myth of state largesse to illustrate some the problems in this area as well.

Myth of State Largesse

Many still think of Canada as a generous welfare state, with conservatives believing it to be overly so. Here, I introduce cases showing that mothers, and sometimes, even disabled children themselves, must fight for even meagre levels of support. In our system of disability supports, caregiving mothers may need to attend court to contest decisions concerning even minor forms of support they require.

In *Brazeau v Canada*, a Tax Court of Canada case heard in Quebec in 2010, the mother appealed an assessment of her return under the *Income Tax Act*.¹⁰⁹⁹ She was assessed as ineligible for the child disability benefit for her son. At the time, the government had decided that the time spent caring for the (medically) disabled boy was less than the required threshold of 15 hours per week in order to be eligible for the tax credit.¹¹⁰⁰ Acting on her own behalf, the mother explained the care requirements of her son as a result of his medical condition, which was Type 1 diabetes. By providing a summary of the time she spent maintaining a balance between her son’s hypoglycemia and hyperglycemia using insulin injections, she argued that his care requirement was considerable and met the established threshold to qualify for the benefit. Maintaining the balance was challenging because her son was involved in sports, which affects blood sugar levels.

The dispute concerned the exact amount of time spent daily on care, with two healthcare workers giving evidence and providing slightly different estimates. The court opined that the calculations used were arbitrary. Although the court appeared to be satisfied with the mother’s evidence, the government

¹⁰⁹⁸ Gilmour & Martin, *supra* note 933 at 372.

¹⁰⁹⁹ *Brazeau v Canada*, 2010 TCC 546, 2010 DTC 1377, [*Brazeau*].

¹¹⁰⁰ *Ibid* at para 4.

asked the boy to testify himself as to the amount of time spent on his condition-related activities. In his decision, Justice Tardif remarked “I have no reason to dismiss the testimony of the appellant's son; he seemed very credible to me, and moreover, the respondent likely granted the same quality to the young man, as he testified at the respondent's request.”¹¹⁰¹ The court held that that the appellant was eligible for the child disability benefit for the months claimed by the mother and ordered her not to have to pay costs. There is something inherently distasteful about this case. The credit is only available to parents with children under age 18, thus, a medically disabled minor was called to testify in a proceeding by a party adverse to his mother, who is the very person who provided and oversaw his care. It is also a case that underscores the quintessentially relational aspects of caregiving mothers and their disabled children in support law. Mothers have to be prepared to “do battle” with government lawyers. It is widely understood that caregiving mothers advocate. What is not always appreciated is that doing so in legal settings actually comprises a part of their burden of care.

Some disputes, like *Brazeau* and the case below, reveal the zealousness of the opposing party to prevent litigants from getting the support they seek. A government that purports to support the rights of disabled children, and to be concerned about maternal poverty, must question why cases like *Brazeau* arise. Such cases provide evidence of wrongful and aggressive refusal of entitlements to state support, which is not state largesse.

There are other examples of government putting obstacles in the way of mothers with severely disabled children in need of support. In response to a provincial government decision, the mother of a disabled child was put through a protracted and complicated legal dispute in her quest to obtain increased state support in *N.S. (Community Services) v E.M.* Determined to access greater than six hours of respite every two weeks from the Nova Scotia Department of Community Services for Persons with Disabilities Program (the SPD Program), she sought additional funding through a provincial respite program.

To appreciate the particulars of this case fully, consider this: there are 168 hours in a week, and many caregiving mothers are on call for all of them. In this case, the government was willing to provide coverage for three out of every 168 hours, and would not waver from this determination. On the mother's internal appeal (ministerial review), the decision to deny respite funding was affirmed. Respite was denied on the basis that the child already received above the maximum amount of time permitted under a departmental Ministerial policy directive. The court decision relates that “she” sought respite funds under the *Employment Support and Income Assistance Act*, also unsuccessfully. ‘She’ is presumably the mother, and not the child client. This is not a minor point, for it begs the policy question of what respite is, and for whom it is offered. Technically, the respondent child was the client of the SPD Program, not the mother.

¹¹⁰¹ *Ibid* at para 13. This case was translated from French into English, as noted in the reported decision itself.

The mother appealed that decision to the Assistance Appeal Board (AAB). When the AAB awarded the mother a modicum of additional funding for respite, the province brought an application for judicial review of that decision on four different grounds. The state was determined to cover every possible avenue to prevent paying additional support. At the appellate court, Mr. Justice Murphy summarized in respect of the appellant mother as the mother having only limited respite of a maximum six hours every two weeks. The judge noted the letter from the physician indicating potential health problems for the mother if she did not get sufficient respite and mentioned also an affidavit expressing this. He noted also that the evidence indicated that there was no alternative care facility¹¹⁰² available in this area at that time.¹¹⁰³ Of the Province's position, Mr. Justice Murphy summarized that the Department stated that they had reviewed the application under the wrong program, and were now asserting that respite is defined as time away from providing care, meaning the caregiving mother's time at paid work qualified as respite.¹¹⁰⁴ The implications of this are that mothers must deal with a legal institution (the Ministry and its governing legislation and policy) that will not stop short of making unfounded arguments in order to deny litigants support.

The affidavits of mothers who bring claims to court do not directly form part of the sources drawn upon in this project, however portions of their affidavit evidence appear reproduced by judges in their decisions.¹¹⁰⁵ In its reasons for dismissing the application for judicial review brought by the Department of Community Services of a decision of the AAB,¹¹⁰⁶ the Supreme Court of Nova Scotia held that the government's application for judicial review should be dismissed. The court examined several issues closely,¹¹⁰⁷ and concluded that the government department had erred in how it had assessed the mother's application, as well as in its characterization of the policies available to support persons with disabilities. The court held that the policy was specific in allowing additional respite and support, and it pointed to a 2006 directive, which stated that policies and regulations *were not to be overridden*. The

¹¹⁰² The intervenor's factum of the Family Alliance of Ontario brought the matter of shortages in provincial supports to mothers in another case, *Vivian* (2012), discussed below.

¹¹⁰³ *E.M.*, *supra* note 577 at para 4.

¹¹⁰⁴ *Ibid.*

¹¹⁰⁵ I mention this because it seems absurd that mothers with severely disabled children must engage in civil litigation at all. It is also absurd that non-lawyer mothers are subjected to the rules of evidence and legalistic disputes. This mother survived the rigours of litigation, with one of her affidavits not being accepted by the court as it was ruled untimely. Why her affidavit would not be let in and dealt with without prejudice is something worth thinking about. Government in this case was not abiding by its own policy provisions, and yet mothers are held to strict timelines in respect of drawing that to the attention of the court. Moreover, the mother's affidavit may contain material that might "clear up" the situation. However, clarity was not the government's aim, support refusal was.

¹¹⁰⁶ The Assistance Appeal Board supported the mother's request for funding for respite. *Ibid.*

¹¹⁰⁷ Such as the relationship between the directive the mother relied upon and other departmental policy, the interpretation of respite by the government, issues pertaining to legislative authority as well as the mother request for funding.

court also noted that the directive was advertised, commenting the mother had relied on it to increase her respite. The Court added that the AAB decision not to admit new evidence should not be disturbed.

The situation in this case demonstrates that even though there was a new policy, the provincial bureaucracy continued to try to subvert the mother's legal claim, which is an important broader point. Given its mandate to provide support, why it engaged in this litigation ought to be critically queried. The tricks and traps commonly used in litigation were brought to bear, as seen with the province's allegation that the AAB had *misinterpreted* the meaning of respite in its decision to increase funding.¹¹⁰⁸ The government's audacious assertion that respite time calculated under its program included when the mother was away from her unpaid complex care and included the time she spent at her paid work reveals a level of unreasonableness that is hard to fathom.¹¹⁰⁹ The government pursued this approach even though respite is clearly defined otherwise in its own departmental Direct Family Support Policy.¹¹¹⁰ A woman faced with this situation could not but acquire a changed awareness of her position *vis-à-vis* the state.¹¹¹¹

To summarize, in an effort to prevent this mother from accessing a few more hours of respite, the government: (i) attempted to alter the meaning of a legally defined word specific to the provisions in question; (ii) tried to circumvent the government's own respite policy directive respecting allowable increases; (iii) reframed disability support as somehow welfare; (iv) presented its argument from a hypothetical perspective of the applicant daughter residing in a home, rather than in the full-time care of her mother; and (vi) acted against a mother in need who had health problems and who was seeking a benefit to which she was entitled. In this type of setting, mothers learn to problematize how the law has been applied to them and their disabled children. In so doing, they discredit government and uncover the myth of state largesse, along with any notions of state benevolence they may have had.¹¹¹² In the present

¹¹⁰⁸ *Ibid* at para 7.

¹¹⁰⁹ *E.M. supra* note 577 at para 4.

¹¹¹⁰ *Ibid* at para 28. Respite is the relief provided to the parent, family, guardian or an individual with a disability, for a specific period of time. The main function of respite is to provide the Individual with a positive and rewarding experience while at the same time providing the primary caregiver with a break from care and the supervision of their family member with a disability.

¹¹¹¹ The government also argued, unsuccessfully, that the daughter's needs ought to be paid for pursuant to that province's social assistance legislation. Justice Murphy set out the government's position as follows: had the daughter not been cared for at home by her mother, "she would presumably be in a home for special care or community-based option home and thus should be covered by the *Social Assistance Act* provisions governing 'persons in need' living in those facilities." *Ibid* at para 25.

¹¹¹² Other examples of intransigence on the part of government were seen in *Nieberg* and also *S.(J.) (Litigation Guardian of) v Nunavut*, 2006 NUCJ 1 [S.(J.)]. Regarding the *S.(J.)* case, a Nunatsiaq News article, Jim Bell, "Treat Disabled Child Properly, Judge Orders GN", *Nunatsiaq News* (17 February 2006) online: nunatsiaqonline <http://www.nunatsiaqonline.ca/stories/article_print/7418>, carried the subheading that Justice Johnson stated "This type of approach causes extreme stress to the individuals and reflects poorly on the government." Naming oppressive practices, this article describes actions and legal positions taken to terminate treatment and support by two government departments, Health and Social Services and Education in Nunavut. This included terminating funding for this severely disabled child's nutrition supplement, which was medically required. The result of that government's determination was that the child's health deteriorated. Claiming that the Nunavut government was

culture surrounding mothers who need support, the work is not to apply for support, but to figure out how to wrest it from officials tasked with “protecting” the public purse.

Myth Surrounding Enforcement of Support

The purpose of this chapter is to expose a series of prominent myths in the area of *public* law as it affects caregiving mothers. The rationale for doing so is to show that although supports may appear in statutes, and may be widely assumed to exist in the culture, it does not necessarily flow from this that such support will be realized by those in need of it. However, although private law support is legally separate from public law support, there is interaction between them. An example of this is where mothers rely on the state to enforce their private law support arrangements. I refer to separation agreements made by the parties and court ordered child support or child support orders issued by the courts on consent of the parties.

In Ontario, the *Family Responsibility and Support Arrears Enforcement Act*¹¹¹³ governs the province’s collection of support from those payors in default and mothers who have made arrangements with government to collect their support. Section 7 of the *Act* provides 11 circumstances in which enforcement may not take place. The reasons provided overall appear reasonable. For example, where enforcement is of a nominal amount, or deemed to be impractical, or where the payor is in prison for five years or longer; where the recipient cannot be located, or where the payor is receiving Ontario Works or ODSP benefits child support, enforcement is not required. The problem is that outside these particular reasons that stand between mothers and child support there are others that defy satisfactory explanation. Not mentioned is how much legal aid is willing to pay to chase an absconding or delinquent payor.

Based on the quantum of arrears across Canada, I argue that there is a lack of state resources put into child support payment enforcement by the same governments who state they expect children to be supported through private child support obligations. The failure of the provinces to comprehensively enforce support represents a failure of public law support to mothers.¹¹¹⁴ This is not only a failure

harming their disabled child through decisions not to fund or properly treat, the family obtained an interlocutory injunction in the Nunavut court. One example amongst many provided in lengthy affidavit evidence provided to the court, was that Dr. Eisenbarth at Baffin Regional Hospital sought to have a referral for the child made to Montreal approved on an urgent basis, and that it took almost a month to approve that request for referral approved. Justice Johnson warned the government not to engage in this conduct with respect to other disabled children. This case provides an example of the many unique problems faced by severely disabled children in general, but also of severely disabled children in under serviced remote regions. Of note, this child was receiving services in Montreal but the parents wanted the child to attend the W. Ross Macdonald School for the Blind in Brantford Ontario. Jurisdictional issues as well a funding issues arose on the facts of *S(J.)*.

¹¹¹³ *Family Responsibility and Support Arrears Enforcement Act*, SO 1996, c 31.

¹¹¹⁴ See Holly Moore, “‘Deadbeats’ Across Canada Owe More than \$3.7 Billion in Support”, *CBC News* (1 Oct 2014) online: <<http://www.cbc.ca/news/canada/manitoba/deadbeats-across-canada-owe-more-than-3-7b-in-support-1.2782955>>. This report states that two-thirds of all child support orders are in arrears and that 97% of those in

domestically, but it also breaches international law. Art. 3.1 of the *CRC* stipulates that “In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”¹¹¹⁵ When considering what can only be called a myth in relation to *comprehensive* enforcement (collection), one must question what happened to the disabled child’s best interests? As noted in my literature review, disabled children are costly children. Art 2. 2 provides that States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures. One of the duties of the other parent legally is payment of child support owing, in its different forms. A state serious about support would do more. The problems associated with child support are particularly galling in the setting of the medically disabled child, whose costs of care may range from high to astronomical.

Myth of Accessible Health Care

That government supports the healthcare needs of Canadian citizens as a matter of course is a view shared by many. Yet, as noted, in the current era mothers with severely disabled children have been tasked with the performance of challenging forms of health care. As noted in the methods section, legal cases provide valuable information about disability care. Although core healthcare is to be funded by the state, in family law cases, insights into the challenges in this area may be found.¹¹¹⁶ I refer to the following case here as it sets the stage for my discussion of another case, one concerning provincial homecare. These two cases ought to be read together as they present a picture of how myths may interact. *Remillard v Remillard* involved appeals from orders for child and spousal support related to the support of a severely disabled child. In it, the child, “E.”, who had medical conditions such as chronic infections and seizures and had been hospitalized many times, was described by the trial judge as requiring unique full-time care. Having raised a child with chronic life-threatening infections myself, I can attest to the difficulties regarding complex forms of care this mother encountered.¹¹¹⁷ Of note, the parties’ second, also medically disabled child, had died two years after the separation. While the case refers to the parents’ commitment to the care

arrears are attributed to fathers. If this is correct, then some mothers are in arrears, too. Yet, Premier Wynn is quoted as stating the problem is not as grim as this statistic suggests. With respect, I disagree. This calculation of arrears is taken from court orders that were filed with provincial child support enforcement agencies. These arrears represent only a portion of child support payment arrangements made between parents. Therefore the \$3.7 billion figure actually represents *only a portion* of the arrears in child support owing today.

¹¹¹⁵ *CRC*, *supra* note 880, art. 3.1.

¹¹¹⁶ Discussed in detail in Chapter Seven.

¹¹¹⁷ See also *Remillard v Remillard*, 2014 MBCA 101 at para 33, 310 Man R (2d) 204 [*Remillard*]. E. required pummeling on her chest and respiratory medication throughout the day. Her throat also needed to be suctioned throughout the day and she required tube feeding four times a day.

of E. during the marriage, the father qualified as an engineer during the marriage, while the mother had not worked outside the home nor obtained further qualifications since E.'s birth. It is the mother who provided extensive evidence about E.'s health needs. *Remillard* unveils legal and societal expectations concerning all forms of care embedded in family law; it is that *health care* is maternally performed, alongside the harsh and unrealistic expectation of maternal economic self-sufficiency, should the former breadwinner object to support.

An issue addressed on appeal in this case was the trial judge's statement that "[t]he *Divorce Act* places the legal obligation on [the mother] to work towards self-sufficiency". She held that "at some point in accordance with this obligation, it was incumbent on [the mother] to begin the process of becoming self-supporting."¹¹¹⁸ Even though there was ample evidence about the health care needs of E. before the court, and even though this is not what another case, *Moge v Moge*,¹¹¹⁹ stated regarding women from longer-term marriages, (which the appellate court decided 16 years to be), I argue the presumption seen in this 2014 case is rampant in many such cases.¹¹²⁰ Note however that *Moge* did not discount the idea of striving for self-sufficiency but confirmed it as one element under the *Act*.¹¹²¹ Moreover, interacting with this mythical presumption are the forms of health care, as explored in *Remillard*, which support this myth. With respect to the mother's obligation to become self-sufficient the trial judge reviewed evidence given by third parties¹¹²² that E. was entitled to 50 hours of caregiver support a week given the nature of her condition, and that she may be entitled to more. The conclusion drawn was that this caregiver support would permit maternal economic self-sufficiency. The reality behind this and other such claims about 'available' care were that the mother only had at most 20 hours of care per week, and not reliably enough to satisfy any employer she could work.¹¹²³ What is astonishing about this case is the trial judge's comment that since the mother "has a thing for clothes" she could work in retail and that since "she also has first-hand knowledge of the care of the disabled" she could find work in that field.¹¹²⁴ Presumably she meant working as a personal support worker for another disabled person, if she got the training, if someone would hire her, if she could leave the house and do so reliably. The mother's healthcare activities for E. were seen by the trial judge as obligation-avoidance in the setting of separation but as comprising suitable work in the setting of the public domain. *Remillard* serves as an example of the fallacy of the private/public divide in the setting of a mythical accessible health oriented care. One ought

¹¹¹⁸ *Ibid* at para 107.

¹¹¹⁹ *Moge v Moge*, [1992] 3 SCR 813, 99 DLR (4th) 456 (*Moge*, cited to SCR). *Ibid* and discussed throughout the decision at the Supreme Court of Canada.

¹¹²⁰ My view is based on what I have seen professionally and experienced personally.

¹¹²¹ *Moge supra* at note 119.

¹¹²² Such as that provided by the Self-Managed Care Program. *Remillard, supra* note 1117 at para 25.

¹¹²³ For example, for administrative reasons their funding was placed on hold at one point. *Ibid* at para 95. Ignored too is the night time care required of mothers with children with complex care needs.

¹¹²⁴ *Ibid* at para 26.

to bear *Remillard* in mind when considering the shortfalls and administrative problems in state provided homecare care revealed in the next cases I examine.¹¹²⁵ They reveal that legal expectations that caregiving mothers work to fully self-support must account for the realities of outside care provisions.

What is taking place in public law provisioning in the area of homecare in Ontario may be described as politically volatile. As the literature showed, many mothers have brought their situations forward to media. *LS v Community Care Access Centre Perth County* was a homecare case brought in 2004. *LS* is a valuable case in which the mother raises important issues. It concerns the homecare services for a 14-year-old girl with a rare genetic condition, and her mother.¹¹²⁶ The facts are that the girl had been approved to receive the then maximum number of nursing hours allowed under the *Long Term Care Act* of 1994¹¹²⁷ and Regulation 386/99. It was an agreed fact that the appellant had not received the number of nursing hours to which she was entitled, eligible and approved for. In her 2002 appeal regarding her Plan of Service the mother listed cutbacks to her daughter's nursing care, and asked to have the hours restored. The mother's (daughter's) revised grounds of appeal are illustrative of policy problems that create hardship for mothers.¹¹²⁸ To summarize, on appeal, the mother sought: an increase of night shift hours to a maximum of 7 nights of 9 hours per night (she stated she needed 63 hours a week which was more than the 53 RPN hours per week the regulation permitted);¹¹²⁹ incentives to encourage nurses to take night shifts and remain longer on a case; the implementation of a back-up plan with the hospital so that booked CCAC nursing shifts for medically fragile children's services need not be cancelled; case management for both night shift and school coverage with greater expertise in these sorts of cases; reimbursement to the mother of money she spent to pay for night shifts that were within the responsibility of her CCAC; authorization to hire RPN's in addition to the RN's for 4 hours in evenings, as respite should the MCSS continue with SSAH funding; hiring of more nurses by the CCAC in Perth so that her daughter's nurses were not so frequently reassigned and so frequently alternated with the cases of other medically fragile children.

¹¹²⁵ See Marcy White's article, "Lack of Accountability in the Health Care System" *HER Magazine* (3 November 2016) online: <<http://hermagazine.ca/lack-accountability-healthcare>>, is an example of the administrative nightmares one Ontario mother is battling.

¹¹²⁶ A case brought in tort might have been the more appropriate avenue, which this mother, on her own, would not have known nor been able to bring forward. However, it too would have a low likelihood of success. Progeria is also called Hutchinson–Gilford progeria syndrome.

¹¹²⁷ *Long Term Care Act*, SO 1994, c 26, it has since been renamed the *Home Care and Community Services Act*, SO 1994, c. 26.

¹¹²⁸ One sees that the caregiving mother must assert the claim of right to care for her daughter, but which is in reality for herself as well.

¹¹²⁹ *LS*, *supra* note 359, under the heading "Issue 1", this case does not have typically numbered paragraphs.

This case draws attention to shortages of nurses and therefore homecare services.¹¹³⁰ While nursing hours are made available by the province in its policy for children with complex health care needs, in practice there were insufficient nurses for eligible service-approved children. That policy and practice do not match is important information, for it is here that another question of accountability and state obligation arises. Of note over a decade after *LS*, this situation has not changed. What makes *LS* an interesting case is that the appellant mother did not simply complain about low levels of service, poor organization or weak coordination of services, she theorized as to reasons why her and her severely disabled daughter's needs were not being met by the provincial health care system. Furthermore, she attempted to link services covered by the hospital, which she saw as more reliable, with unreliable nursing services in the community. She offered ideas of how to improve services in the setting of what she believed to be funding shortages. She had therefore extensively problematized the barriers she and her daughter had faced and suggested alternatives to the CCAC. Problematization is part of praxis, which may lead to critical consciousness. After a review of the mother's revised ground of appeal, the Health Services Appeal and Review Board (HSARB) dismissed the appeal, finding the CCAC did not treat the Appellant as ineligible to receive service, nor decide that a service would be removed from her plan. The HSARB also noted that no decision had been taken by the CCAC respecting the amount of service to be included in her plan of service, nor to terminate the provision of service.¹¹³¹ However, I note this is beside the point as her/her daughter's eligibility for service was not the issue, the failure of the CCAC to provide the approved level of nursing care was the issue.

Other statements of the HSARB reiterate the problems identified by the mother at the policy level. The Appeal Board acknowledged in its decision that the CCAC was not filling the at-home nursing shifts, but it did not address the presence or absence of the CCAC's legal obligations to do so, nor the ramifications to the mother in its failure to do so. The Appeal Board accepted the submission of the CCAC that it is "making every effort" to provide nurses under the care plan, and did not find CCAC derelict in its duties towards the appellant. This begs the question as to what exactly those duties are. The Board was legalistic in its explanation of the mother's circumstances, an approach that allowed it to step away from the facts, which provided evidence that the support needs were not being met, irrespective of the intention of the CCAC to do so or not to do so.¹¹³² This case makes clear that the administration of nursing services are not structured to meet the mother's or the child's care needs, but rather to facilitate

¹¹³⁰ Ontario has proposed amendments to *Provision of Community Services*, O Reg 386/99, which would allow CCACs to provide extra care, above the usual maximum numbers of visits or hours, to clients with extraordinary needs. "Proposed Amendments to Regulation 386/99 under the Home Care and Community Services Act, 1994 Relating to the Provision of Community Services" online: Service Ontario <<http://www.ontariocanada.com/registry/view.do?language=en&postingId=18703>>.

¹¹³¹ *LS*, *supra* note 359, under the heading "Decision", second last page of the decision. Original emphasis.

¹¹³² There are limits on the jurisdiction of the Board.

and protect those administering them. It also points to the uncertainty mothers live with respecting nursing care. Even though the Appeal Board accepted that this girl “requires a great deal of care and support,” that issue was not the focus of the case; the technical aspects of what regulations do and do not provide were the focus.¹¹³³ This is telling as these defenses to the allegations take precedence over other features, such as how the girl’s health is or how the mother is managing this crisis.

There are indications in the reading of *LS* that this mother had been demanding, having made suggestions, and having refused to receive personal support workers--whom she believed needed greater expertise-- instead of nurses. Her position was understandable, given that even now, little is known about Progeria, her daughter’s rare condition. This mother is a caregiving pioneer in a maternal wilderness.¹¹³⁴ In their research on complex paediatric homecare Manhas and Mitchell state: “Mothers were attributed with extraordinariness given the range of burdensome responsibilities they completed as well as their approach to such completion ... occasionally extraordinariness was negatively viewed as aggressive.”¹¹³⁵ Maternal extraordinariness was indeed assumed by those professionals mentioned in the decision (managers, nurses), as well as by the Appeal Board Members. The assertiveness of the mother in this case may also be seen as evidence of a willingness to engage in conflict, which is something Montero states those with acquired critical consciousness are prepared for as a result of the push provided by their restructured consciousness.¹¹³⁶ In this dispute, the push came in the form of a mother fighting for professional care for a medically fragile child for whom she was responsible in a system she perceived and which this decision demonstrates, failed to fulfill its obligations to provide approved nursing care.¹¹³⁷

¹¹³³ Mothers also appeal health care decisions respecting their medically disabled children under the Ontario Health Insurance Plan. These are beyond the scope of this project.

¹¹³⁴ In a google scholar search for mothering a child with Progeria, which I conducted to learn what a mother’s needs in this particular medical setting might be, nothing came up. According to a British news article, there are only 74 documented cases of Progeria in the world. “Britain’s Oldest 20-Year-Old Man Has the Body of a 160-Year-Old Due to Rare Condition, *DailyMail* (25 April 2012) online: Daily Mail Online <<http://www.dailymail.co.uk/health/article-2134367 -Dean-Andrews-20-body-160-year-old-rare-condition.html>>.

¹¹³⁵ Manhas & Mitchell, “Extremes, Uncertainty and Responsibility”, *supra* note 199 at 233.

¹¹³⁶ Montero, “Consciousness Raising”, *supra* note 130 at 7. There is an implication in this decision that the CCAC found the mother demanding. She was demanding, she was demanding the CCAC meet its obligations to provide nursing care to her and her daughter.

¹¹³⁷ More recently, disability activist Audrey Cole, mother of Ian Cole, a middle-aged man described as severely disabled, brought a complaint of discrimination (as his litigation guardian) against her local Ontario CCAC with respect to Ian’s homecare services. In *Cole v Ontario (Health and Long Term Care)*, 2016 HRTO 497, The Ontario Human Rights Commission intervened asserting that the regulation was discriminatory based on disability and was not protected as a “special program” under the *Code*. The HRTO decided that the CCACs ought to have discretion to increase visits, such that persons medically in need of more care, could have it. An alternative ‘reading’ of the governments submissions in this case are that if his mother, now in her 80’s, could not provide his medical care, by performing it or paying for it, then Ian should be living in an institution. The now 88-year-old Audrey Cole is still battling for her son’s rights and, by extension, her rights (she is the one paying for his care). Given the choice between Ian being placed at risk of infection and her paying money privately that she cannot afford to pay, she chose to pay. Like the case of “Mrs. E” discussed in Chapter Six, the facts of *Cole* exposeh societal myths. One of these is

Although I have made my point, which is that health care has been unavailable to caregiving mothers in forms they articulate are needed, I nevertheless provide a final but important case to underscore the point that government has not cooperated with mothers' efforts to access care in the past.

Auton v British Columbia also illustrates an aspect of the myth of comprehensive health care.¹¹³⁸

In *Auton*, parents, along with their children with autism, sought to have the British Columbia Ministers of Health, Children and Families, and Education, fund "treatment" for older autistic children. The first named party was the Minister of Health. As noted in the later litigation, the province sought to "de-health" the government's benefit provisions to autistic children, by taking them out of the responsibility of the provincial Ministry of Health and reassigning them to another Ministry. In spite of that, the *Auton* litigation has retained its characterization as a healthcare lawsuit. In rejecting the claim, the Supreme Court of Canada noted that the province did not hold out that it funded all medically necessary required treatment, only those insured core services, limited to physicians and hospital care. The court also pointed out that the province had discretion not to do more than that.¹¹³⁹ The difficulty is that the mothers of many children with severe *medical* disabilities find that they are the ones responsibilized for medical care as a result of how health care is now being defined and apportioned.

At the time that the *Canada Health Act* came into force in the 1980's, there was legislation in respect of the institutionalization of disabled children, and autistic children were routinely institutionalized.¹¹⁴⁰ While the model of care has been shown not to have accorded with children's rights, the fact remains that state-funded care was the norm.¹¹⁴¹ This is not the case now, with mothers largely replacing the state in providing support to disabled children. This means that the state withdrew its monetary support from these children, and the fact that the model of care the state funded was highly unsuitable does not change the fact that expensive childhood disability support were once in place in recent past. Tuohy, a health policy theorist, suggests that health policy changes when rare windows of

'retirement' where caregiving mothers are concerned. Cole has been battling for Ian's rights for decades and is almost 90.

¹¹³⁸ *Auton* (2004), *supra* note 1139. Comprehensiveness is another aspect of the *Canada Health Act*, RSC 1985, c C-6.

¹¹³⁹ The British Columbia Supreme Court had found that the equality rights of autistic children and their parents were infringed by the government. *Auton v British Columbia (AG)* 2001 BCSC 220, 2001 197 DLR (4th) 165.

¹¹⁴⁰ Institutions were still being built in Ontario the 1960s. See Ministry of Community and Social Services, *The Evolution of Government Policy and Legislation: 1839-1960* (Toronto: Queen's Printer for Ontario, 2012) online: <<http://www.mcass.gov.on.ca/en/dshistory/legislation/1839-1960.aspx>>. Strong-Boag's article "Children of Adversity", *supra* note 369 at 421, mentions Ontario's Orillia institutions housing disabled children, and includes mothers' perspectives, including on the heartbreak of one mother in institutionalizing her multiply disabled four year old child.

¹¹⁴¹ As evidenced by a series of lawsuits launched against government. One of these is *Dolmage v Ontario*, 2010 ONSC 1726.

opportunity manifest, but that often internal policy constrains states from making changes.¹¹⁴² At the time of the aforementioned *Auton* decision, cutbacks in social and health care spending and structural reform between the federal and provincial governments resulted in privatized care. Meanwhile there was no expansion of what the *CHA* requires provinces and territories to pay for, and which remains focused on physicians and hospital services. Provinces have the discretion to decide to fund other types of health services, or not. Arguably, the ideology of privatization, at the intersection of the influences on policy Tuohy mentions, pulled the most weight.

Conclusion

My critique of public law supports for caregiving mothers with severely disabled children has shown that a variety of factors prevent mothers with severely disabled children from advancing and securing legal rights to support. These include the vast public monies dedicated to government litigation compared to the meagre financial resources of litigating mothers, the presence of broad discretion in interpreting support policies of the state, and the prevalence of conservative bureaucratic approaches to supports. It also includes unequal power to bring and defend claims for support, and other extra-legal features such as the impacts of myths that circulate about caregiving mothers, and that are embedded in law and in approaches to resolving legal disputes.

In my next chapter, I address mothers' efforts to assert claims to support through private law and private law's interplay with and co-dependence on public law. Not only does public law require mothers to pursue private avenues of support, but government makes efforts to use that support to claw back what the state provides. Therefore, caregiving mothers may find themselves in two or more contested proceedings simultaneously in relation to support.

¹¹⁴² See Carolyn Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain, and Canada* (Oxford: Oxford University Press, 1999). Tuohy refers to many factors that as influencing government health policy decisions around the time of the *Auton* litigation.

CHAPTER SEVEN: Private Lawsuits

Introduction

In the previous chapter, I examined caregiving mothers' legal efforts to access support from government and the obstacles they encountered. I presented as obstacles a series of myths that get put into play in legal proceedings and that may stand in the way of mothers' rights to public support being realized. In this chapter, I examine mothers' efforts to obtain support from private parties, rather than from government, and I do so by examining cases from across provinces and jurisdictions, dating from the 1980s. I examine caregiving mothers' family law claims to support, as well as support claims brought in other areas of civil litigation. Again, I do this by critiquing as myths assumptions in law that get applied to mothers with disabled children. These myths either play out implicitly, or they are explicitly deployed by opposing parties.

In the previous chapter I named and examined myths encountered and resisted by caregiving mothers in public law. These myths revolved around issues of maternal autonomy, child abandonment and child protection, equality, ordinary motherhood, political leadership, state largesse, state enforcement of support and in the area of health care. There is some overlapping of myths named in chapter six with those named in this chapter, however some of the myths are unique to the private sphere. In this chapter I address primary myths as follows: that caregiving mothers are like other mothers and should and can become financially independent as quickly as possible; that the measure for support of the normative child has applicability to all children; that security for sole-support caregiving mothers is possible without robust state support because family law provides support; that actual co-parenting can occur in settings where children have severe disabilities and that the other parent can be assumed to lessen the care burdens of sole caregiving mothers; that caregiving *per se* is not materially different than mothering; that disabled people are not fully adults; that disabled people 'take it easy'; that the welfare state is robust and generous towards caregiving mothers and disabled people in accordance with its obligations and as such, family law support need not be paid.

None of these myths are grounded in reality. Yet, they get told by law and through law, about those who are seeking support, over and over again, in the course of negotiations and litigation. The aim of the myths seen in private law is to ensure that a version of care that responsabilizes mothers to the greatest extent possible is upheld. That way, the realization of rights to support remains remote and it is largely the mother who will bear the costs of such support.

Another part of my argument is that some mothers gain the awareness that their lives as caregivers have been mythologized, and that myths are used against them to influence the course of justice. Consider for example, the conservative value that support of children ought to be dealt with in the

private sphere. In this context mothers naturally and self-sacrificingly provide care. When this value is leveraged in law, care burdens may be rendered invisible. Myths, such as that it is natural for women to mother under all circumstances, do much ideological work in the support cases I examine involving mothers with severely disabled children. The damage to caregiving mothers and their disabled children is evident both from the inside, where such myths are embedded in legislation, and from the outside, as they appear in the submissions made by payees and their legal counsel. Rather than it being a given that heavy care burdens require extraordinary support, the onus of rendering burdens of care visible is on mothers and their legal counsel. These myths, as I show, damage mother's claims even before they are put in legal documents, and they may continue to damage their claims to support throughout legal proceedings.

Feminist legal scholar Mary Jane Mossman points out that if social problems are characterized in a manner that does not reflect reality, state policies will not solve them.¹¹⁴³ I have shown how the state characterizes disability-related care as a benevolent and gendered responsibility. If state provisioning is not likewise benevolent, as it purports to be, then its representations of care are inaccurate. Myths buttress state positions as to whose obligation it is to provide disability care to children. Freirian theory holds that myths are used to subordinate, and this, I argue, can be seen in private support law and policy. As this chapter will show myths that appear in family law also corral maternal and child legal claims for support. They also serve to mask truths about need of support, and as such they further allow untruths about need to be deployed in submissions by those who seek not to support mothers with severely disabled children.

Mossman provides the example of government having determined the social problem of lone mothers and their children living in poverty as best solved through private law. She states that the solution to the problem of support of children was found in the creation of *Federal Child Support Guidelines*, a government tabulation that, she argues, re-privatizes the social problem of child support as one of "dead-beat dads" (non-paying fathers). The myth is that if fathers would only pay, lone mothers and children would not be poor. The cases I discuss below, weighed down by myths, show that private law is not an answer to the poverty that may arise in the setting of disability.

The myth of the sacrificing mother is a harmful trope in the policy narrative of the burdens of disability (discussed in Chapter Four). However it appears also in ordinary policy and in normative mothering discourses as well, but not so blatantly. Child support purports to alleviate mother-child poverty, which is seen as comprising *private* problem and which calls for *private* action to resolve. There is a galling assumption that mothers do not object to this, when in fact we do. The reality is that non-support paying fathers are passively protected in their non-payment of state-imposed support obligations

¹¹⁴³ Mary Jane Mossman, "Child Support or Support for Children?: Re-Thinking the 'Public' and 'Private' in Family Law" (1997) 46 UNBLJ 63 at 64. Here, she references Nick Manning, "What is a Social Problem?" in Martin Loney, ed, *The State or the Market: Politics and Welfare in Contemporary Britain* (London: Sage Publications, 1987) 8. This time frame coincides with significant changes in the welfare state, including severe cut backs in welfare.

owed to mothers by weak state accountability mechanisms, and by a cultural tolerance for paternal support-evasion. Non-paying fathers are tarred with the label of ‘deadbeat dad,’ something the state hopes will shame them into paying support. However, statistics would suggest that the label has no such effect.

Mothers do not typically evade care obligations, which are an almost exclusively gendered form of child support, although not seen nor tallied as such in law. As discussed in the literature review, economists have found ways to measure the cost of support of a disabled child. These measurements need to be incorporated into law, and valued.

Where family law support is concerned, I aim to show through an examination of the above-noted myths, that caregiving mothers’ claims to support are ‘trapped’. This metaphor corresponds with Nancy Fraser’s notion that structures of dependency are created by the capitalist welfare state, and are used to contain the support needs of mothers as private.¹¹⁴⁴ This is in keeping with the political theory of the welfare state of Nancy Fraser. She argues that struggles that take place over the denial of political status of a need have validated as legitimate a political concern, so that it is not enclaved as non-political.

Arguably too, family law individualizes as financial pathology the support problems mothers with disabled children bring to family court, and as such, family law bears similarities to the medical model of disability, locating the problem in the persons to be “fixed”. In practice, some family lawyers encourage support payor compassion, goodwill and guilt, not unlike the charity model.

Another aim is to show that family law offers a window into caregiving mothers’ lives. Counter-intuitively, these cases are useful because they highlight vulnerability and dependency not only where mothers have separated, but where they were partnered, as well. They reveal that some unions could not survive the stressors imposed by situating complex care in the family. This challenges a position taken in critical disability studies that refutes negative impacts of care provision to disabled children on parental relationships. That view holds that having a child with severe disabilities has little or no effect on relationship stability, or on rates of separation.¹¹⁴⁵ Family circumstances prior to separation vary, but public supports remain consistently low, irrespective of that. This is true regardless of legal arrangements between parents.¹¹⁴⁶ Disabled children live more often outside marriages, a fact also challenging the view that unions are not affected.¹¹⁴⁷ Important information for policy is that what is already highly gendered

¹¹⁴⁴ Nancy Fraser, “Talking about Needs”, *supra* note 4 at 294.

¹¹⁴⁵ See Dick Sobsey, “Marital Stability and Marital Satisfaction in Families with Disabled Children: Chicken or Egg?” (2004) 32:1 Developmental Disabilities Bulletin 62.

¹¹⁴⁶ See discussions in Cohen & Petrescu-Prahova, *supra* note 362. See also Carnevale et al, “Daily Living”, *supra* note 360 at e54, where one interviewee states 80% of people with an ill child will separate.

¹¹⁴⁷ See Susan Boyd & Claire Young, “Feminism, Law and Public Policy: Family Feuds and Taxing Times” (2004) 42 Osgoode Hall LJ 545, state that family law discourses ignore that race, sexual orientation, class and aboriginal status affect determinations in family law. There is also a need to consider the effects of disability. Cases show that that spouses who could not relate to their disabled child or the care they require *prior* to separation, proved unable to provide respite to mothers *after* separation.

care, may become exclusively so in the setting of separation. Those claiming that marriage is unaffected by mothers' unmet care needs ought to examine the literature that includes interviews in which caregiving mothers recount information about their relationships with spouses, as well as the body of relevant family law cases.

Family law cases also reveal why some caregiving mothers have involved child welfare agencies in care. This addresses another debate within critical disability studies as to whether or not maternal health is impacted by care in current policy settings. Family law cases can valuably reveal perspectives on the obligation of the state or other parent to provide support.¹¹⁴⁸ Perspectives of those unwilling to pay, or unwilling to pay more than they do pay, are fleshed out in legal proceedings.¹¹⁴⁹ Also exposed is that some support payors rely on the inherent limitations in family law: for example, the ability to contest quanta of extraordinary expenses, the ability to delay proceedings, and weak state enforcement of and possible expungement of arrears as a means to avoid paying support that disabled children require. Evidence given in such cases further demonstrates hardships mothers may encounter in such proceedings.¹¹⁵⁰ Also relevant, in family court documents,¹¹⁵¹ are claims made by payors as to the state's obligation to support their disabled child. These often omit the mother's contributions, and on such occasions, family court judges may usefully shine a light on mothers' hidden care performance and the implicit and explicit costs of the care they provide.¹¹⁵² This is all 'data' that policy-makers ought to attend to in considering support.

Fathers paying and not paying child support have been a focus of family law litigation generally. Where for typical children, non-support paying fathers are seen to pose an obstacle to expressed state interests in reducing child poverty, in the setting of disability, ways to privately shore up mothers' capacity to provide complex care are looked to. Refreshingly, some family court judges have commented on weak state supports and the ramifications of that on mothers rather than blaming mothers for 'social problems' related to children having disabilities. In so doing, these judges play a crucial role in confronting the deeply troubling myths that may otherwise block access to support, privately.

¹¹⁴⁸ These are apparent in the submissions of mothers, facta of disability organizations, children's lawyers (see *Vivian* (2012), *infra* note 1237) and in legal positions taken by fathers.

¹¹⁴⁹ See Dana Lee Baker & Laurie A. Drapela, "Mostly the Mother: Concentration of Adverse Employment Effects on Mothers of Children with Autism" (2010) 47:3 *The Social Science Journal* 578 at 587, make the point that conflicts "increase the caregiving workload on the mother, thus decreasing her ability to participate in the labor force." They are referring to disputes mothers in the United States experience with insurance companies. But the point they make may be applied to support the position that litigating for support takes time, energy and money away from caregiving mothers.

¹¹⁵⁰ Curiously, few of the cases I came across were brought before a judge as a matter of urgency or hardship.

¹¹⁵¹ It must be remembered that some parties agree and other settle out of court, as not all separations are high conflict.

¹¹⁵² Cases providing examples of this are explored in depth below. Home, *supra* note 241, describes the fact that it is hidden as oppressive.

Myths Encountered in Private Law Disputes

The aim in this section is to show what it is like for a sole mother to navigate the layers of complexity that must be dealt with in order to access supports. At the heart of this complexity are the pervasive social myths that circulate around mothers with severely disabled children. It is useful to examine the text of legal cases to see who puts which myths into play, and why. This helps one to apprehend the work that myths do and to see whether putting them into play in a court case has been successful or not. For example, a party might rely on a myth as a vehicle to discredit the character of a support-seeking mother. However in its decision, the court may be oblivious to the myth, play into it, or it may in fact challenge the myth. Such an examination can aid in a better understanding of the harm caregiving mothers encounter as a result of having to confront pernicious myths along the path to support. I now turn to consider some examples of legal cases, which demonstrate the above noted myths, and how they are used in litigation.

The Notion of ‘Private’ as Legal Myth

Family law, when described as ‘private’ law, presumes a civil law arrangement between individuals dealing with a domestic matter away from the state. However, family law matters cease to be private when child welfare becomes involved, or when the state is involved in collecting child support, or when social assistance professionals are in court with mothers to ensure they are pursuing their child support claims. Then, proceedings are subjected to state scrutiny and involvement. Thus, while the means of support sought through family law are private, what takes place in family courts may be public.¹¹⁵³ Susan Boyd and Claire Young state that, “the characterization of family law as purely private, or the notion that family law exclusively regulates private relationships between individuals and families is out of date.”¹¹⁵⁴ Boyd and Young point out that its public aspect arises in that family law provides an arena for public issues to be litigated. They refer to taxation,¹¹⁵⁵ child and spousal support, and constitutional law as

¹¹⁵³ In the Notice of Constitutional Question in *Coates v Watson*, the Court referred to public law disability rights cases, such as *Granovsky v Canada (Minister of Employment & Immigration)*, 2000 SCC 28 *Coates Ibid* note 871 at para 108 and *Eldridge v British Columbia (Attorney General)*, 1997 3 SCR 624 *Coates supra* note 871 at paras 104 and 109 in its reasons for finding there to have been *Charter* rights infringements in a statute pertaining to private law disability support obligations.

¹¹⁵⁴ Boyd & Young, *supra* note 1147 at 554.

¹¹⁵⁵ Taxation is an area that calls for much greater levels of attention in many areas of support law. In Linda McQuaig, “Tax Loopholes hiding behind gentler fronts” *Toronto Star* (28 September 2017) A15, McQuaig states that “Brian Mulroney’s Conservative government introduced a tax change beneficial to wealthy families owning private trusts. One of the arguments used to justify the change was that it would help families with a trust to support a disabled child.” She added that “the image of helping a disabled child certainly softened the image of what the government was doing.”

examples of this.¹¹⁵⁶ As well, the legislative framework itself regulates families and in this sense it too is public. The cases I examine below show that the boundary between private and public law is not only blurred when caregiving mothers seek support, but traversed.

It has been stated that “[l]iberal theory has not traditionally acknowledged the extent to which family policy and family law inevitably reflect political decisions and choices.”¹¹⁵⁷ Caregiving mothers learn this through their involvement in family law. Through support claims, some caregiving mothers challenge the political and even legal underpinnings of family law itself, consciously disrupting definitions and legal terms of art, forcing courts to struggle with caregiving mother’s ill-fitting fact patterns. Some seek to expand legal provisions that affect them, including in those domains overlapping with family law, such as child welfare and social assistance.

Caregiving mothers have described the space where public support policy and private family law support overlap as *increasing their burdens*.¹¹⁵⁸ This description points to a critical awareness on their part, that the state does not recognize the value of disability care, and will battle not to have to provide or support it. This framing also positions the state as hostile to caregiving mothers’ interests. Accordingly, I argue that no family law case involving support for disabled people, age of majority or not, is truly private. This myth must be borne in mind in the cases below.

The Masculine Myth of Independence

Another myth caregiving mothers confront in family law is that of independence following separation and divorce. The majority of men are financially independent at separation. However, women who are also mothers, and in particular, those with severely disabled children, are much less likely to be able to be or become financially independent. Moreover, independence can mean different things, and the concept has not been fleshed out in Canadian family law where caregiving mothers are concerned. The reality is that rather than becoming *financially* independent after divorce, even many typical mothers go on to become poor.

In addressing obstacles to a mother’s ability to become independent after separation, and referring to the Supreme Court of Canada decision in *Moge v Moge*, Turnbull states that excluding support

¹¹⁵⁶ *Janzen v Janzen*, 2014 BCSC 1374 [*Janzen*], is an example of a family law support matter interacting with public law. The court examined where the non-custodial disabled mother’s disability pension child benefit portion (which she electively paid as child support to the father) fit in relation to the calculation of her spousal support. The impoverished mother, sought interim spousal support, which the respondent agreed she was entitled to. The mother received CPP disability benefits, with a small amount of social assistance. Her income was under \$11,000 a year. She paid the children’s benefit portion to the CPP to the father as child support. Moreover, the case was reported, being reviewed here, making it public.

¹¹⁵⁷ Minow & Shanley, *supra* note 209 at 6. Marella states that family law is a product of legal consciousness of thought of classic liberalism, at 4.

¹¹⁵⁸ See Tolmie & Bachmeier, *supra* note 967.

payments, 74-percent of divorced women had incomes below poverty lines.¹¹⁵⁹ This reality is seen in case after case, such as in the cases of high-functioning caregiving mothers like Diane King and Vivian Courtney whose legal cases I address below.

Notably, as the literature review explored, disability adds to risk of impoverishment in ways revealed in the cases I discuss. One of family law's aims is to provide support, but it is not always able to ensure that support is realized. This is its greatest failing where disabled children and their mothers are concerned.

Regarding law's failure towards women in general, the Hon. Bertha Wilson stated, "We have had to face the fact that making women's equality a reality, whether within the family or outside it, poses complex issues incapable of a simple doctrinal resolution."¹¹⁶⁰ Her statement is particularly apt where caregiving and disability are concerned in family law settings. Family law was not enacted as a means to support disabled children nor complex caregivers. It was designed with the normative family in mind. As a result, caregiving mothers in making their claims for support, must try to 'make do' with its under-inclusive and absent provisions. The fact that this law is not "for" them, reflects their status misrecognition. Family law is itself unjust in its omissions.

Much has been written about child and spousal support in the setting of the non-disabled child, but very little has been written about support for severely disabled children and their mothers, other than by family court judges in their decisions and a handful of lawyers.¹¹⁶¹ For the severely disabled child, family law disputes are largely about support, although disputes about medical treatment may take place as well.¹¹⁶² To varying degrees, it is disability support and healthcare that are in dispute in these cases,

¹¹⁵⁹ Lorna A. Turnbull, *Double Jeopardy: Motherwork and the Law* (Toronto: Sumach Press, 2001). Turnbull does address disability with the view that tax policy needs to be more sensitive to parents with disabled children at 172.

¹¹⁶⁰ B Wilson "Privacy", *supra* note 717 at 29.

¹¹⁶¹ Christine Dobby, "Whose Responsibility? 'Disabled Adult Children of the Marriage' under the Divorce Act and the Canadian Welfare State" (2005) 20 Windsor Rev Legal Soc Issues 41, points out that the definition of adult child of the marriage under the Divorce Act must be contextualized. By that she means situated in the economic and social context of the mother, who most often is the primary caregiver in the setting of single parenting. *Ibid* at 46. She argued that both federal and provincial family legislation must be reformed to reflect reality. To do so, she states the tension between public versus private obligations in the support of adults with disabilities must be resolved. She suggests a partnership approach. *Ibid* at 54. Her paper is often cited by family court judges on issues of support for adult disabled children. See also Griener, Griener, Abby L. "Evidence Based Analysis of the Spousal Support Advisory Guidelines in Alberta" (Paper delivered at the Canadian Bar Association Alberta, Alberta Law Conference, 30-31 January 2014) online: Vogel Lawyers <<http://www.vogel-llp.ca/~ASSETS/DOCUMENT/PDF/2/A2D2-00093939.PDF>>.

¹¹⁶² I came across one case where the father sought joint custody with the mother of their two sons. In recent years, family courts have recognized that while joint custody may seem ideal, in practice it is not always suitable. I argue that this may particularly be so in the setting of disabled children. In *Krone v Krone*, 2011 NLTD (F) 7, 305 Nfld & PEIR 96 at para 59, the court held that "Mr. Krone does not have the same ability or willingness (as Mrs. Krone) to provide his sons with guidance and education, the necessities of life, or attend to Dominic's special needs pursuant to s 31 (2)(d) of the *Children's Law Act*." I did come across two reported cases where the father had custody. In one case, *Janzen*, *supra* note 1156, discussed elsewhere in the dissertation, the mother had advanced MS and was unable to provide the care and needed care herself.

although this is not made manifest; consequently, care is treated as though it is ordinary mothering, and therefore considered private in nature.

There is no family law doctrine in respect of mothers who provide health care, social care, and disability support, often for their life or the life of their disabled child into adulthood. Since family law is about parenting, and not about medical or disability care, medical care and disability support are transformed into “parenting” in this area of the law. This feature ensures that caregiving mothers cannot in fact achieve a measure of real independence at all. Thus, the autonomy rhetoric in family law is grossly misplaced in relation to caregiving mothers’ family law claims.

Worthy of note amongst the words of mothers and judges in family law cases reviewed across time and jurisdictions are those expressed in *Dunham v Dunham*.¹¹⁶³ Here the parties had two children, of whom one had a severe disability. *Dunham* was a spousal/child support case. In it, the court held that “the wife could not be faulted for not having implemented a plan for self-sufficiency. Moreover, to expect her to handle more than she was presently handling might seriously impact on her ability to care for her children.”¹¹⁶⁴

The *Dunham* court challenged the myth of independence, which relays the message that after separation and/or divorce, men and women are economic equals, both able to continue into a new life, unburdened by incurred responsibilities from the relationship. If this includes caregiving of, for example, a chronically and severely ill child or youth, that ability to regain pre-marital independence is curtailed. Buried within the independence myth is the derivative myth that care is an unimportant factor in whether or not independence is reached by a given mother. Maternally complex care has no firm legal footing in family law presently. According to the underlying myth supporting current family law, after separation, women are emancipated and can continue to build their lives, *unimpeded*. This logic however fails to accord with the realities of complex care or disability support caregiving women face after divorce. It is fallacious to suggest that one can be emancipated as a lone female, under-supported, complex caregiver. It is also to be remembered that family law support was put in place for among other things, to alleviate child poverty. Child support is noted to have its own mythology associated with it. In fact, family law can only be said to hope to alleviate family poverty, to some limited degree, in cases where fathers pay consistent child support in amounts that make a difference. That is not a given, particularly in the setting of severe disability. In fact, it may not even be a given in cases where there is a child with a mild disability and the putative payor of support is wealthy. This information is relevant to a later discussion about caregiving mother’s unique need of support.

¹¹⁶³ *Dunham v Dunham* (1998), 84 ACWS (3d) 294, [1998] OJ no 4758 (QL) (On Ct J (Gen Div)) [*Dunham* cited to ACWS].

¹¹⁶⁴ *A.L.Y.*, *supra* note 1091 at para 58 referring to *Dunham*, *Ibid*.

In the infamous *Dickie v Dickie*¹¹⁶⁵ case, the parties, who were married for thirteen years, had three children. One child had a learning disability. The children lived with their stay-at-home mother, formerly a nurse. At the date of separation, the father was earning \$915,000 annually. Dr. Dickie decided not to pay support, in spite of a family court order ordering him to do so. Lawyer Susan Heakes discusses the prevalence of contempt of court in private support disputes and provides commentary on *Dickie*. In it, a high income earning father was found in contempt of court for refusing to pay court ordered support. Heakes states, “family lawyers see more contempt of court than others in the civil litigation bar. Spouses who refuse to honour agreements and court orders are [she states] aggravating and expensive for clients who respect the system.”¹¹⁶⁶

At some level, it is evident that family law operates in a culture that tolerates this. Caregiving mothers have the right to bring a claim for support, however this right is qualified, as it can be realized only where fathers are willing to pay¹¹⁶⁷; where they are not, the court and the state must be willing and able to make them pay. Through lawyers, mothers can chase fathers, often at high cost and with dubious success. Yet, where children are disabled, non-payment may be catastrophic.¹¹⁶⁸ Even with payment of ordinary child support however, ‘independence’ remains in the realm of myth for many caregiving mothers, unless they make their children wards.

Research findings indicate that all women experience major loss of income after separation.¹¹⁶⁹ Where women are caregivers this has enormous implications, particularly since spousal support is resisted by support payors. Fortunately some courts, like Justice O’Connell in *Dupuis v Desrosiers*¹¹⁷⁰ see with clarity the concerns about caregiving mothers’ support. In *Dupuis* the father did not agree that he should pay any spousal support. His position was that the mother was *underemployed* and *fully capable of finding employment*. The court however included the following in its decision, “[t]he applicant has primary care of a young severely disabled child with special needs which restricts her ability to find and maintain employment at the current time”,¹¹⁷¹ adding that this formed part of her strong claim for support.

¹¹⁶⁵ *Dickie v Dickie*, 2007 SCC 8, [2007] 1 SCR 346 [*Dickie*].

¹¹⁶⁶ Susan Heakes, “*Dickie v Dickie*: Contempt in Family Law Proceedings” *The Family Way* (Canadian Bar Association National Family Law Section Newsletter) (July 2007) online: CBA <<https://www.cba.org/CBA/newsletters/pdf/FAM-Dickie.pdf>> at 1.

¹¹⁶⁷ “Ninety-seven percent of parents trying to avoid child support payments are men, and the problem of women and children living in poverty following relationship breakdowns has been recognized by the Supreme Court.” LEAF, “*Dickie v Dickie*”, online: <<http://www.leaf.ca/dickie-v-dickie/>>.

¹¹⁶⁸ Discourses of independence are placed on disabled children as well. At the same time, disabled children require greater levels of supports to meet that expectation. Schools no longer provide all that disabled children require, and mothers bring such issues to family lawyers to resolve.

¹¹⁶⁹ Celine Le Bourdais, Sung-Hee Jeon, Shelly Clark and Evelyn Lapierre-Adamcyk. Impact of Conjugal Separation on Women’s Income in Canada: Does the Type of Union Matter? 35 *Demographic Research*, Article 50, 1489 at 1489. Online <<https://www.demographic-research.org/volumes/vol35/50/35-50.pdf>>

¹¹⁷⁰ *Dupuis v Desrosiers* 2012 ONCH CANLII 261 para 34

¹¹⁷¹ *Dupuis ibid* at para 34

Poverty is not emancipating, particularly for women with severely disabled children to support. Even with this statistical knowledge, as Alison Didiuk points out, in making everyone ‘autonomous’ post-separation, actual interdependencies are forgotten or treated as though irrelevant in family law determinations.¹¹⁷² Such interdependencies should give rise to relational rights, but do not. This is nowhere more true than where mothers with disabled children require support. Where the legislative scheme views the caregiving mother as an autonomous agent and treats the child as normative, when he or she is not, there is slippage between purported aims of the statute and what really happens.

The masculine myth of independence, which is that parties are independent after separation, hides another reality that affects caregiving mothers child support entitlement. Some men lack the means to pay child support. They may be recipients of state benefits such as Ontario Disability Support (ODSP) for example. This benefit does not even provide a living income.

One can see here how myths interact, working together to prevent caregiving mothers from realizing their right to support. It is to the myth of the assumed normative child that I now turn. This myth remains pervasive in both public and private law, creating havoc with mothers’ claims.

The Ableist Myth of the Normative Child

For sole mothers with disabled children, there may be an opportunity to seek child support through family law channels.¹¹⁷³ Where there is, it may be sought from the child’s father or from another man who has been acting in loco parentis to the child. As well, privately ordered child support arrangements may end up before a judge.¹¹⁷⁴

As alluded to already, child support is predicated upon the needs of the normative child. As a technical matter, there are two aspects to support under the Federal Child Support Guidelines (FCSG). There is the table amount of support, calculated based on the payor’s net income.¹¹⁷⁵ There are also add-on support amount possible under s 7 of the FCSG. Table amounts of support are calculated without reference to the needs of disabled children. Mossman, referencing Carol Rogerson’s review of decisions

¹¹⁷² Alison Didiuk, “Autonomy and Vulnerability in Family Law: The Missing Link” in Julie Wallbank & Jonathan Herring eds, *Vulnerabilities, Care and Family Law* (London: Routledge, 2015) 95 at 96.

¹¹⁷³ Fathers may have died or disappeared. Not all child support-collecting mothers are single. Some are repartnered. Another group of mothers are the so-called astronaut wives who are effectively single mothers for periods of time. Johanna Waters and others have written about the circumstances of these women. See Johanna L. Waters “Flexible families? Astronaut’ Households and the Experiences of Lone Mothers in Vancouver, British Columbia” (2002) 3:2 Social and Cultural Geography 117. These mothers do not have need of family law provisions, but they may well need a range of state supports, especially if the father is in denial as to the child’s disability for cultural reasons.

¹¹⁷⁴ At the behest of a support paying Ministry, or mothers or father seeking variation in support or respecting expungement or enforcement of arrears for example.

¹¹⁷⁵ Calculations are not consistent across Canada, with Alberta having a higher quantum of table support for incomes over \$150,000 than does Ontario for example.

immediately following the *Divorce Act*, shows that table support fails to account even for the costs incurred raising a normative child.¹¹⁷⁶

Another problem is the need for family lawyers and self-representing mothers to attend to s 7 expenses in the child support of severely disabled children.¹¹⁷⁷ This can be futile. Since the guidelines are under-inclusive of the support needs of the severely disabled child, mothers may seek to have courts read their additional needs of support into them or into the add-on support categories. As well “[t]he table amount and sharing of s 7 expenses may not properly reflect the recipient spouse’s full costs of caring for the high needs child.”¹¹⁷⁸ The Federal Department of Justice lists s 7 expenses on its website. It does not include health-related care needs for a chronically severely ill or disabled child in this list.¹¹⁷⁹ As a result, many of the costly health/care needs of severely disabled children are missing in add-on expenses.¹¹⁸⁰ As such, s 7 often presents as legal loophole in the eyes of caregiving mothers.

Although section 7 of the Guidelines was amended in 2006 to provide clarification of how courts and legal counsel are to deal with extraordinary expenses and special expenses,¹¹⁸¹ there remains no specific provision for severely disabled children and their mothers. Special expenses do relate to health related costs, child care and medical expenses, but having to argue that the expenses of severely disabled children or moderately disabled children ‘fit’ within categories is hugely burdensome and expensive if payment is refused. It is laudable that under the new scheme the cumulative impact of extraordinary expenses are to be considered and that special circumstances are structured to allow for courts to consider each case on its particular circumstances, this does not translate into such health related costs being ordered or being collectable. The norms in the FCSG are not easy to exceed and payors can simply state they do not agree to the pay for s 7 expenses, even if they do not oppose the child receiving the service or items for which the mother requests a contribution.¹¹⁸² This amounts to an economic ‘free ride’ to use

¹¹⁷⁶ The legal principles in *Paras v Paras*, [1971] 1 OR 130-136, 14 DLR (3d) 546 (ON CA) [*Paras* cited to OR], was that child support amounts should support children “at the pre-divorce standard of living and that the costs of achieving this standard of financial support should be shared by the parents according to their respective incomes.” Mossman, *supra* note 1186 at 67.

¹¹⁷⁷ These are calculated separately. Section 7 “add-ons” typically include costly items as eye-glasses, dental care and prescriptions, sports lessons and equipment, and tuition.

¹¹⁷⁸ Griener, *supra* note 1161 at 15.

¹¹⁷⁹ The list now includes “child care” as the result of a disability or illness and also the child’s health-care needs that exceed \$100 per year if the cost is not covered by insurance (for example, orthodontics, counselling, medication or eye care). See Department of Justice Canada, “The Federal Child Support Guidelines: Step-by-Step”, online: <<http://www.justice.gc.ca/eng/rp-pr/fl-lf/child-enfant/guide/step7-etap7.html#h9>>.

¹¹⁸⁰ Such as respite and paediatric home care severely disabled children require that goes beyond what the state provides. Moreover, the *Income Tax Act* likewise fails to acknowledge many such expenses.

¹¹⁸¹ See Sheila Gibb, “A Reasonable and Necessary Guide to Section 7. Clothing, Cell Phones and Computers. Oh My!” (2016) 35:3 Family Law Quarterly 212. At 215, Gibb states the FCSG were amended to provide clarity.

¹¹⁸² For example, to have a psycho-educational evaluation of the disabled child undertaken for scholastic purposes. In my experience, these cost from \$3000 to \$5000 presently.

Nancy Fraser's phrase.¹¹⁸³ The right to claim s 7 expenses is one of the weakest rights caregiving mothers have and one of the most costly to get a contribution towards, so much so many caregiving mothers simply do not bother.

There ought to be a section under the FCSG termed "the disability care contribution." This amount is neither 'special' and although 'extraordinary' in terms of their high cost, they ought not be dealt with as though they fall into that category, as such costs are ordinary where disabled children are concerned. Complex care is different from hockey equipment or ballet lessons.

In some jurisdictions, family courts have begun to acknowledge these shortcomings. In 2012, an Alberta Bar Association paper revealed some courts opining that the child support needs of separated mothers with disabled children exceed guideline amounts. This has been recognized in respect of spousal support quanta too.¹¹⁸⁴ Having Bar Associations tackle the myths that surround caregiving mothers in this way is helpful. This same paper observed that, "a child with special needs can affect the ability of the primary parent to obtain or maintain full-time employment, meaning that the duration of support might be extended beyond the time limits used by the With Child Support Formula (length of marriage/last child finishing high school)."¹¹⁸⁵

Such recognition from the Bar and in the case law presented by speakers at the Alberta Bar conference, helps to undermine the myth of maternal independence in the private law setting as well as that of the ever-present normative child. The point to be made is that problems in the difficult area of family law supports are hugely magnified in the setting of support for the severely disabled child.

A final point in this section is on ablesit myths of the normative child in family support provisions as has been noted in literature, that some payors cannot afford to pay support.¹¹⁸⁶ There is thus the mythology concerning adequacy of child support *to support mothers in need of it*, however, the implications of this myth amplifies where severe disability is present.

Myths of Security and Certainty in Law

The existence of family law litigation exposes the myth that family law will ensure the financial security

¹¹⁸³ Nancy Fraser, "Contradictions of Capital and Care" (2016) 100 New Left Rev 99 at 101. Fraser states that capitalist economies rely on free rides, and mentions caregiving as an example. She states such economies fail to attach a monetary value to care treating forms of care as if they are free.

¹¹⁸⁴ Griener, *supra* note 1161.

¹¹⁸⁵ *Ibid* at 15. She adds "[w]ith respect to variation of the amount, using the higher end of the SSAG range may provide the extra funds required to account for the recipient's lower income, but in some cases, it may be necessary to go above the high end of the range."

¹¹⁸⁶ Mary Jane Mossman, M. J. "Child Support or Support for Children? Re-Thinking the "Public" and "Private" in Family Law" (1997) University of New Brunswick Law Journal, 46, 63 She states that little research has been undertaken in this area but unless we are to assume that all non-payors are deadbeats there are financial problems faced by fathers as well at 64.

of disabled children and their caregiving mothers. In fact, one of the reasons laws are enacted is to try to ensure a measure of certainty in people's financial affairs. Certainty is of interest to payors, and appears to be a primary interest for many. It is also described as bringing finality to the pesky issue of monthly payments. However, caregiving mothers seek security for their disabled children, over certainty or finality.

The 2006 Ontario family law/estate case, *McAdam Estate v McAdam* demonstrates that s 7 expenses are important forms of private support. In *McAdam*, the parties were partially through their divorce when Lynn McAdam, one of the parties, died. The parties had a 16 year-old daughter, Heather, who had an intellectual disability. Heather's legal guardians were her maternal uncle, Norman Willet, and aunt, Sherri Willet, and not her father. A family court order required the father to pay for her extraordinary expenses, which included her special needs worker, tutoring, summer camp fees, and a LiveWorkPlay Program. The father was in receipt of a Canada Pension Plan survivor benefit as a result of his wife's death. He subsequently sought to have more than half of his disabled daughter's s 7 expenses be paid from his dead wife's estate, which she had bequeathed to their daughter.¹¹⁸⁷

The court held that the \$60,000 left to Heather was intended for her future care and ought not to be depleted "in the face of Mr. McAdam's ability, and primary obligation, to meet Heather's extraordinary expenses."¹¹⁸⁸ The court held that to do otherwise would not be in her best interests. This case shows that the mother was aware that Heather would require her support in the future. With her mother's death, Heather had an uncertain future. During her lifetime, Lynn McAdam argued that programs for children with disabilities ought to be "special expenses" under s 7 of the FCSG. Although she was successful in doing so, her estate faced a *post mortem* attempt by the father to unseat the court order that the mother had put in place to protect their disabled daughter.

McAdam illustrates that even where private support has been legally arranged, disabled children of caregiving mothers are at risk of challenges to it. The *McAdam* court agreed with the deceased mother's expressed wishes to provide security to her disabled daughter, to the extent that she could. The myth of security is illustrated in this case as it shows how vulnerable to attack private support arrangements are, particularly in the setting of childhood disability in cases where payors seek to reduce or terminate support.

¹¹⁸⁷ *McAdam v McAdam*, 27 RFL (6th) 182, 2006 CanLII 12323 (ONSC) at para 7. The father contested swimming lessons (\$40 every 6 weeks) and the Liveworkplay program. In an endorsement, *McAdam v McAdam*, 27 RFL (6th) 182 at para 4, 2006 CanLII 12323 (ONSC), Madam Justice Linhares de Sousa refers to the "intensity of the conflict" in this case.

¹¹⁸⁸ *McAdam*, *Ibid* note 1187 at para 22.

The myth of security includes the idea that caregiving mothers can actually be secure under present systems of supports and that family law is able to help ensure this.¹¹⁸⁹ One aspect of this myth is the erroneous belief that once caregiving mothers have full-time employment, they will be able to self-support. As noted above, family law policy has yet to deal with employment expectations in the setting of caregiving mothers.

The security myth is similar and tied to the myth of independence. It may be true that mothers can find their footing in the labour market after their caregiving-influenced patterns of labour force participation, but it is not a given, even with typical children. Where children do have less severe disabilities, it may be the case that their mothers have managed to work and remain healthy while performing maternally complex care. Whether or not this juggle is even possible depends on many factors, some of which were explored in *A.L.Y. v L.M.Y.*¹¹⁹⁰

A.L.Y. is helpful because it shows that even where a caregiving mother has all that family support anticipates -- her health, child support, a full-time job -- she still requires more support to function than do others. To deny this is to deny the actual costs of disability and the effects of childhood disability on the security of the mother. *A.L.Y.* was an application for spousal support brought by an Alberta caregiving mother of a 13-year-old girl with multiple disabilities. She was employed full-time as a nurse and the child's father lived nearby. The child was in the interim custody of the mother with table amount of child support being paid by the father. Although the mother worked full-time, and although she received child support, she successfully obtained an order for spousal support.¹¹⁹¹

In *A.L.Y.*, the judge was willing to put disability support into court ordered support.¹¹⁹² Ordinarily, a mother working full-time with a well-paying position who is also receiving child support would not be

¹¹⁸⁹ Family lawyers and academics know this is not true, but many separating mothers do not.

¹¹⁹⁰ *A.L.Y.*, *supra* note 1091.

¹¹⁹¹ The issues before the court were whether there should be an order the spousal support, whether there should be a lump sum payment to reimburse the mother for costs of the child's medical care and child care and the appropriate s 7 (add-on) child care expenses. The final issue was whether there should be an order for costs.

¹¹⁹² *Cf. Cosh v Cosh*, 2010 NBQB 265, 358 NBR (2d) 311. *Cosh* concerned claims for extraordinary expenses, child support arrears, and spousal support by the mother. The mother was to have custody on consent of a grade 1 autistic boy. She claimed she could not work full time as result of her sons' disability, which required her to be up nights, amongst other things. The court, commenting on the mother's employment situation, stated that she had more time to work with the expenditures she was making for the child. (at para 2) Distinguishing *Cosh* from *A.L.Y.*, Justice Baird ended his decision with the comment that "Mrs. Cosh cannot put her life on hold any longer." *Ibid* at para 153. In so doing he put his finger on the big issue, while also refuting caregiving was an issue on these facts in the same way as it was in *A.L.Y.* Of interest, the court noted the objectives of spousal support as recognition of the economic advantage or disadvantage arising from marriage breakdown. Yet the court pointed to the short-term marriage and the mother's same level of work at the outset of the marriage as at the end, along with insufficient disclosure as reasons for the court not to award sought after support. However, the court also opined that an award of spousal support could negatively affect her 'subsidy income'. The court stated that the mother had financial support from her family and a sympathetic employer, *ibid* at para 26. At the time of separation she worked part time at Pizza Delight *ibid* at para 20, and during the litigation she did shift work at a dollar store (at para 30). I note that she did not have an autistic child before the marriage, but this was apparently not material to the issue of economic disadvantage

able to show the requisite need of such support. This mother sought spousal support with the aim of having it cover the cost of respite care she required. While the father submitted that he would exercise access as respite for the mother, there were barriers to that. First, his new partner did not feel comfortable around his disabled daughter, so access was being exercised in the home of his own father, who was ill. Second, the father was an alcoholic who drank when his daughter was in his care. Although there was child support being paid, a second parent on the scene, a potential stepmother figure and an income-earning mother, this mother was effectively a single, working mother with a multiply disabled child in her full-time care. Not everyone is fit to provide childhood disability care, but this does not mean the only one who is should be responsabilized for all of it.

The court noted that the mother received some respite coverage for one weekend a month from Handicapped Children Services, but that state respite was not available. The court held that when a place did become available, the father was to pay the \$200.00 per weekend and \$40.00 charge for each additional day of respite.¹¹⁹³ In reaching her finding, Justice Johnstone examined the respite care family law cases.¹¹⁹⁴ In light of s 15(2) (6) (b) of the *Divorce Act*, which provides that the court may apportion between the spouses any financial consequences arising from the care of any child of the marriage over and above any obligation for the support of any child of the marriage, she determined self-sufficiency did not preclude an award of spousal support on the facts of this case.

Her Honour's interpretation in this case challenges mainstream understandings of maternal autonomy, and does so in a way that supported this mother's security and well-being, in a way usual judicial interpretations have not. The quanta of support set out in support guidelines, as well as amounts of support discussed in precedential and other family law cases, seems as though such amounts actually do "support" and do not merely comprise a contribution to support in both normative child support and where disability is a factor. In other words, she challenged the prevailing myth of security that I argue is embedded in family law. The court opined that it is the wife who suffers economic disadvantage on separation, based on the traditional division of labour in marriages, stating that the primary "economic disadvantage generally arises from child care." She added, "this is not the only vehicle by which a wife may be disadvantaged financially" and in so doing, acknowledged that the care of a disabled child may be another.

Finding that the aim of compensatory support was to compensate the disadvantaged spouse from the effect that these sacrifices have had on his or her economic well-being, Justice Johnstone awarded

resulting from the marriage in *Cosh*. The Judge states "I recognize that Mrs. Cosh has assumed a loving and caring role for Zachary. She is doing, and wants to do the best she can for him, to ensure that he receives the proper treatment for his autism. She is to be commended for her hard work." at para 151. Again we see mothers responsabilized and the work of care unvalued beyond the value of praise.

¹¹⁹³ *A.L.Y.*, *supra* note 1091 at para 21.

¹¹⁹⁴ *Ibid* at para 25.

spousal support.¹¹⁹⁵ She opined that child and spousal support are based on different principles, stating, “Recognizing the financial consequences of the care of a child is not the equivalent of recognizing the child’s own need for support, although the two concepts are obviously often closely related.”¹¹⁹⁶ She added that child support is a mutual obligation of the parents that, like access, is owed to the child. In awarding spousal support to a working mother in receipt of child support, Justice Johnstone stated that the courts must examine the pattern of financial interdependence generated by each marriage relationship “and devise a support order that minimizes as far as possible the economic consequences of the relationship’s dissolution.”¹¹⁹⁷

In this case, then childhood disability then was seen to have significant consequences on mothers. The court drew attention to a portion of the decision in *Dickson v Dickson* that, “[t]he provision of some respite for Mrs. Dickson from the constant care of Christopher provides an example of financial consequences to a spouse of caring for a child, over and above the direct costs attributable to the child.”¹¹⁹⁸

This judge’s opinion should have far-reaching implications, as it addresses crucial issues taken up in other important family law cases. In the literature review, it was shown that caring for a disabled child is a social determinant of the mother’s health. In *A.L.Y.*, we see it is also a social determinant of economic survival. This challenges the myth of the lazy, unmotivated, or unambitious mother, and also the myth that the costs of care of a disabled child can be easily absorbed with full-time work and modest state help.

Even in instances where separated fathers agree that a higher than table amount of child support should be paid where there is a disabled child, this does not translate into security for caregiving mothers. In *Morrison v Morrison*, a Yukon case, the father brought a variation proceeding to rescind his child support arrears.¹¹⁹⁹ It was inferred by the court that he had agreed to pay a higher than table amount of support because the parties’ children had disabilities. Other facts were that, as the court stated, the father provided little respite even though the mother had a serious medical condition. The mother’s physician had indicated that she ought not to work full-time but she worked three and a half days a week to support her children. When she was not performing paid work, she was providing care.

Getting fathers “on board” with the realities of *disability care* through family law entitlement to claim support is not a realistic solution. Mothers ought not to be expected to rely on the good will of men they are no longer involved with, when research reveals gendered patterns of disability care that family law cannot remedy. This leads us to the next myth.

¹¹⁹⁵ *Ibid* at paragraph 33, she states she took directly from C. Davies, “Spousal Support under the Divorce Act: From *Moge* to *Bracklow*” (1999) 44 Reports of Family Law (4th) 61.

¹¹⁹⁶ *A.L.Y.*, *supra* note 1091 at para 37.

¹¹⁹⁷ *Ibid* at para 38.

¹¹⁹⁸ *Ibid* at para 49. See *Dickson v Dickson* (1987), 46 DLR (4th) 280, 11 RFL (3d) 337, (BCCA).

¹¹⁹⁹ *Morrison*, *supra* note 106.

The Co-Parenting Myth in Childhood Disability

There is debate in the literature on the challenges of shared custody, and feminist critiques of it, as well. Such critiques focus on power and relationship issues that may make such arrangements unsuitable. Such an arrangement requires the ability of parents who have not been able to remain together to find ways to agree in the custodial domain of medical care, as well as parenting. It is also to be remembered that even in the case of the normative child, joint custody does not mean shared parenting. Co-parenting, I argue, is a myth perpetuated by an ideal of joint custody, and in the setting of the severely disabled child post-separation there are potentially safety concerns associated with it if parents cannot agree as to the child's medical care arrangements.¹²⁰⁰ Conflict concerning complex care increases a mother's care burdens.

It is not only custody arrangements that may pose a threat in cases where parents of severely disabled children cannot agree, so too may access arrangements. Thus, lack of legal attention paid to access for children with complex care needs after separation or divorce increases caregiving mothers' burdens. This may not appear as significant a problem as non-payment of child support to disabled children, but cases I examined did reveal that in some instances, for a variety of reasons, fathers did not seek to exercise all of their access or wanted no access at all.¹²⁰¹ This may leave the lone mother providing care continually.

Jans v Jans involved a 21-year marriage and claims by the mother for arrears in child support for three children, aged 13, 20 and 23. In *Jans*, the mother also brought a claim for spousal support. She stated that she cared for the parties' 13-year-old child, a boy with Down Syndrome (Logan), who required continual supervision, and that she did not work outside the home. The judge commented on the fact that the father was to have exercised access to Logan once a month, but chose not to, and describes the father as "abandoning" his son.¹²⁰² The judge found that where one parent is the primary or sole caregiver of a severely disabled child, spousal support should be ordered at a slightly higher rate than the spousal support guidelines (SSG) recommend.

Abandonment by a biological father in the setting of typical children in family law cases is not unheard of. However, in the setting of disability, the ramifications of it are significant not only to the child, but also to the mother. *Jans* is helpful in that Justice Kvill tabulates the disabled child's extraordinary expenses. In so doing, the judge determined that being a lone mother with a severely

¹²⁰⁰ The American Bar Association has tacked some of them in a newsletter (but does not address the gendered realities of such situation). See Barbara Epperson, "When Parents of Children with Disabilities Divorce" (April/May 2008) Online: American Bar Association <http://www.americanbar.org/newsletter/publications/gp_solo_magazine_home/gp_solo_magazine_index/parentsdivorce.html>.

¹²⁰¹ As well in some public law cases there is further evidence of this pattern. See for example the case of Cyndy Moore whose husband is reported to have left, *Siemens Milltronics*, *supra* note 1040.

¹²⁰² *Jans*, *supra* note 1090 at para 6.

disabled child is an economic hardship. This is not to be confused with stating that a disabled child is being constructed by the *Jans*' court as being an economic hardship. The court stated, that "the mother's role as sole caregiver to a disable[d] child needed to be considered"¹²⁰³ as she had full responsibility for Logan. The judge also commented that the burden of caring for a disabled child had financial consequences for the mother, such that she was unable to pursue education or work full-time. She opined that the mother's first obligation was "always to care for Logan", who may require support for life.¹²⁰⁴ Unfortunately, this is not a situation family law on its own can remedy. At best, a small portion of someone else's income may be transferred.

Jans found that support was needed to "*relieve any economic hardship of the spouses or adult interdependent partners arising from the breakdown of the relationship.*"¹²⁰⁵ The judge stated, "The breadwinner father left this relationship with his income earning ability. The mother was left to continue to care for the children and she struggled to financially support those children. Recently the father stopped providing that... support."¹²⁰⁶ Further noting that s 60 (d) of the *Act* which sets out "*Insofar as practicable, promote the self-sufficiency of each spouse or adult interdependent partner within a reasonable period of time,*"¹²⁰⁷ *Jans* found that it was "not satisfied that the Spousal Support Advisory Guidelines sufficiently takes into consideration the fact that the mother is solely responsible for the financial effects of having to care for a disabled child."¹²⁰⁸

McAdam, A.L.Y. and Jans all reveal features of economic risk inherent in being a sole caregiving mother. These cases reveal that after separation, even where the mother has died, fathers may not be seeking involvement in care, even though in many family law cases, custody and access is hotly contested. When contemplating levels of support to award where support is being litigated, family courts need to recognize that actual shared *caregiving* --as opposed to 'parenting,' which is not the same thing -- is not the norm where children are severely disabled, and that mothers are unlikely to find relief from the other parent except in unusual circumstances.

Although fathers' parental roles are represented in Canadian culture as changing, research shows they remain the secondary parent.¹²⁰⁹ Their parenting still fits around work schedules, unlike for mothers, who remain primary parents with care responsibilities of a different order.¹²¹⁰ I argue there needs to be caution vis-à-vis assumptions made about co-parenting applied to disabled children/disabled adult

¹²⁰³ *Ibid* at para 33.

¹²⁰⁴ *Ibid.*

¹²⁰⁵ *Ibid.* Italics in original.

¹²⁰⁶ *Ibid* at para 34.

¹²⁰⁷ *Ibid.* Italics in original.

¹²⁰⁸ *Ibid* at para 39.

¹²⁰⁹ Glenda Wall and Stephanie Arnold. "How Involved is Involved Fathering? An Exploration of Contemporary Culture of Fatherhood?" (2007) 21: 4 *Gender & Society*, 508, at 522.

¹²¹⁰ *Ibid* at 522

‘children’ that make it appear as though the caregiving mother would be well supported by the other parent in a joint arrangement. Cases show a myth of co-parenting appearing in family law in different ways. In *Favrod*, (discussed above) the court opined that the circumstances showed the parents endeavoured to share in the *responsibilities* involved in providing quality care for their severely physically and mentally disabled daughter.¹²¹¹ The father however was able to both work and pay support. It is unclear from the facts the extent to which they actually shared care. In another case, the myth is exposed by the mothers’ evidence. In *Madden* the father sought termination of the order for joint custody and an order for sole custody of the parties disabled child. The mother sought to maintain the joint custody order, which had been made on consent. The child had learning difficulties, ADHD, asthma and allergies. Justice Jones stated the parties had always had difficulties with childcare. She awarded sole custody to the mother, finding the father was not accommodating the child’s special education or medical needs. For a caregiving mother the opposite of support is the failure of a co-parent to provide needed care.¹²¹²

This myth seems particularly troubling when we have federal public law cases like *Canada AG) v Johnstone*, a family status case involving the allocation of shifts to a mother in the workplace, in which the Federal Court (upheld on appeal) acknowledged the social role expectations on mothers to provide care as different from fathers. These expectations must be accounted for in support law. Otherwise, even in settings of joint custody or sole custody with some, little or no access in the setting of disability, caregiving mothers are responsibilized for the costs of virtually all forms of care.

Caregiving mothers are conscious of this. For example, Ontario mother Robyn Coates sought to have s. 31 of Ontario’s *Family Law Act (FLA)* declared unconstitutional as it did not address the child support required by unmarried mothers and their severely disabled adult children who resided with them, and not with their fathers.¹²¹³ This absent entitlement to bring a support claim made for contentious situations. The title of a recent *Law Times* report on a case brought by Coates and her adult disabled child support was entitled “Challenge Over Child Support Leads to Showdown. Judy Van Rhijn reported the case was about “the last area in family law where there was abject discrimination against unmarried parents.”¹²¹⁴ The reporter saw a battle concerning child support. Coates saw unjust support of disabled adults and their mothers.

¹²¹¹ *Favrod supra* note 958

¹²¹² *Madden v Richardson* [2004] OJ No 1532 (QL)

¹²¹³ *Coates supra* note 871.

¹²¹⁴ Judy Van Rhijn (March 6, 2017). Challenge over Child Support Leads to Show Down” *Law Times*. <<https://www.lawtimesnews.com/author/na/focus-challenge-over-child-support-heads-for-showdown-13190/>>.

Unlike Nicole Courtney, in her earlier claim in *Vivain v Courtney* (discussed *infra*),¹²¹⁵ the *Coates* court agreed that *Charter* rights infringements of the mother, Robyn, and her son, Joshua, occurred as a result of the fact that the federal statute has a provision for adult disabled child support under the *Divorce Act* (in respect of married or previously married parties), versus the provincial statute under which Nicole Courtney and Robyn Coates were claiming adult child support which *did not* provide for this same form of support for unmarried parties, like them. Thus family law distinguished between disabled children of unmarried relationships and their residential parents, usually their mothers and their married counterparts.¹²¹⁶ This situation arose to begin with because legislative authority for divorce is a federal matter, set out in the Constitution Act, 1867 but support and child custody issues have classically been viewed as “within the competence of provincial legislatures before the federal government’s Divorce Act of 1968.”¹²¹⁷

In pursuing this litigation, Coates signaled her awareness that lack of such disabled ‘child’ support is not only a legal problem for her, but a legal rights problem for other mothers, too. One of these was the ideal of equality ‘for all’ in law versus the reality of their exclusion from a provincial private support regime. Moreover, having perceived injustice in the law, she took action to deal with it. This readiness to dispute the injustice once apprehended is a reflection of critical consciousness.

Justice Sullivan in his *obiter dicta* on the operation of s15 of the *Charter* in this case, stated that s. 31 of the *FLA* “shuts a door to Joshua/Robyn to have a court consider and have an opportunity to assess his needs ...”¹²¹⁸ Thus *Coates* shed light on the myth of shared “parenthood”. Joshua’s father had not been involved with his son, and stated to media that he was throwing himself upon the mercy of the court,¹²¹⁹ hoping to avoid sharing in the mother’s financial costs of his adult disability support.

In terms of the feminist standpoint and critical consciousness framework in this thesis, and in keeping with legal ‘rights’ as I describe them, Coates believed that as a caregiving mother she was entitled to support. What she experienced however was that there was no means in her and her disabled son’s circumstances, to claim it. Their care circumstances were excluded and there was no entitlement to bring the claim under the legislation. Coates did not accept this. At this point she asserted the other kind of right I described, which is rights-claims for support where none exists. She was aware that in its silence

¹²¹⁵ *Vivain* is discussed in detail below.

¹²¹⁶ See *Coates supra* note 871 where in Justice Sullivan held that “Section 31 of the *Family Law Act* of Ontario violates Joshua and Robyn’s section 15 (1) *Charter* rights, and therefore s. 31 of the *FLA* does not apply to the circumstances within Wayne’s Motion to Change before me, dated July 22, 2014, Tab 1 of Vol 3 of the continuing record. Section 31 of the *Family Law Act* is not saved by section 1 of *The Charter* at para 227.

¹²¹⁷ Peter Hogg, “Constitutional Law of Canada” (Toronto: Thomson, Carswell, looseleaf at 27.5) in Mossman et al at 343 Families and The Law. Cases and Commentary. (Concord: Captus Press Inc. 2015).

¹²¹⁸ *Coates supra* note 871 at para 171.

¹²¹⁹ See Laurie Monsebraaten Nov 19 2016 Brampton Mother Seeks Child Support For Disabled Adult Son thestar.com <https://www.thestar.com/news/gta/2016/11/19/brampton-mother-seeks-child-support-for-disabled-adult-son.html>

the law misrecognized her right to do so, something that came across in media interviews with her. Her support rights-claim was based in constitutional law, as noted above. She stated that her aim in pursuing the litigation was so that “no other single parent caring for a disabled child can be abandoned by an absent parent when the child becomes an adult.”¹²²⁰ Her legal advocacy expanded mothers’ legal right to support. Her legal action signaled critical consciousness.

The Myth of Maternal Extraordinariness

The myth of extraordinariness has to do with societal expectations regarding a mother’s ability to provide complex care, with minimal supports. This myth is, I argue, akin to the oppressive notion of the ‘supercrip’ that is applied to some disabled people. This is the idea that disabled people can overcome their disability, and with effort and work, ultimately live in the world as though they are not disabled. The myth of extraordinariness similarly anticipates that caregiving mothers can overcome the burdens of complex care with diligence, effort and hard work, ignoring the fact that to do so is economically harmful and unjust. Such expectations set different standards for women and disabled people than for those who are not pushed to far exceed ordinary limits at tremendous personal expense. This myth is also a means for government to divest itself of the costs of disability support.

Some family law decisions appear to be based on this myth, while others challenge it. *Caldwell v Caldwell*, an Alberta appellate court case involving a claim for spousal support, addressed expectations of extraordinariness.¹²²¹ In *Caldwell*, the extraordinariness myth was in play, even though the mother was herself disabled. Mrs. Caldwell had serious illnesses, and had also provided full-time care to the parties’ disabled children.¹²²² The judge stated that in awarding longer than usual spousal support for a 12-year marriage that “the mother has carried an extra burden as the sole caregiver for four children who have learning, emotional and physical disabilities” and also found her sole care had impacted her ability to work or retrain, issues that “directly affected her earning power.”¹²²³ Notably, the court considered the goal of self-sufficiency (one myth) in the context of extraordinary caregiving (another myth).

¹²²⁰ Laurie Monsebraaten, “Brampton Mother Seeks Child Support For Disabled Adult Son”, *The Toronto Star* (19 November 2016) online: <<https://www.thestar.com/news/gta/2016/11/19/brampton-mother-seeks-child-support-for-disabled-adult-son.html>> [Monsebraaten, “Brampton Mother”] referring to *Coates*, *supra* note 1219.

¹²²¹ At separation, the four children’s ages ranged from 1 to 12 years.

¹²²² She had inflammatory arthritis, lupus as well as gastro-esophageal reflux disease. The children were youths of varying degrees of dependence.

¹²²³ *Caldwell*, *supra* note 1090 at para 19. Things do not always turn out this way. In the Alberta case *BGF* *supra* note 245, a mother with medical problems who worked part-time since separation, was in a dispute with her children’s father, to whom she had been in a long-term married. The 19 years old son, had ADHD, Tourettes Syndrome and asthma as well as learning disabilities, seizures, and medically documented cognitive and behavioural conditions. The other child had also medically documented disabilities that the family physician reported required ongoing support. Although this judge opined that the mother had “borne the brunt of childcare”, *ibid* at para 31, he nevertheless found that “upon the evidence ... **neither child should be considered disabled**. One is now an adult,

Caldwell raises important questions, one of which is why a separated woman with serious health problems was responsabilized by society with primary disability care and was required to absorb the economic and other costs associated with it. Had support not been awarded, this would have comprised hardship.

All of the cases discussed thus far provide evidence that the support needs of mothers with disabled children are different from those of mothers with non-disabled children. While successes may be forthcoming across Canada in respect of support awards in family law, it must be remembered that in order to access this form of support, there must be a payor with means, and a payee with the emotional and financial ability to pursue her claim. It is not, however, my position that caregiving mothers should assume the risks associated with reliance on private support. Their doing so gives lie to the myth of autonomy as well. This is illustrated in the next section, which deals exclusively with private support for adult disabled children, where the myth of autonomy looms large in proceedings.

Adult Children with Disabilities

Where age of majority children are severely disabled, legal myths I rely upon to shed light on obstacles and gaps in support provisions in this domain reflect and reify the oppression of both less well-off women and disabled people. For example, as discussed, in family law there is a myth of (eventual) maternal financial autonomy, which is imposed on mothers through law even where there are severely disabled children whose care stands starkly in the way of that. The normative expectation in separation and divorce is of the eventual autonomy of the child, along with that of his or her mother from the child. Here, the myth presents the adult disabled child receiving financial state support as autonomous from his or her caregiving mother.¹²²⁴ The normative post-separation expectations of self-sufficiency and its accompanying myths imply that an autonomous caregiving mother can get on with her life and career in mid-age, free of care, worry, and related financial burdens and without need of support.¹²²⁵

To the extent that these myths operate in family law, they suggest that mothers with severely disabled children are not fully legal subjects. I say this because the care such mothers perform and the

and one soon will be. Whether they remain dependent upon Ms. F. appears to be a decision on their part and on their mother's part." *Ibid* at para 32, my emphasis. This decision represented a failure of the court to "see" disability, rather than the implication made that the mother saw disability where none existed. The mother's ongoing care disappeared in this case, along with the disability. *BGF* was referred to in Griener, *supra* note 1161 at 15. The mother in this case had a set of expectations placed on her that required her to be extraordinary. Meanwhile she was dealt with by the court as ordinary.

¹²²⁴ I refer again to Tolmie & Bachmeier, *supra* note 967, whose submission to their MPP entitled *Increasing the Burden Instead of Lightening the Load: The Impact of Current ODSP Policies and Practices on Single Parents Caring for Adult Children with Disabilities* reflects threats to maternal autonomy where single mothers care for adult disabled children in Ontario.

¹²²⁵ Elaine Jones also refers to this in her thesis entitled "Social Reality versus Family Law: The Experience of Mothers of Children with Long-Term Disabilities", *supra* note 155 and it is reflected in private support litigation.

impacts of it on their lives are unseen. As such, their circumstances are, at times, outside the law's reach; they require courts to expand legal meanings established in order to meet their needs.

In a now moot¹²²⁶ Ontario provincial family court case,¹²²⁷ a not-in-paid employment, lone, full-time caregiving mother of a severely medically disabled youth over the age of 18 defended against a motion to end child support for her now late daughter. In *Courtney v Vivian*, the provincial legislation was largely silent on the support needs of mothers with severely disabled adults in their sole care. This allowed payors to make besmirching claims in their submissions.¹²²⁸ This meant that the circumstances of the mother were not legally remediable on a facial reading of the statute in question. I discuss this case with a view to critiquing some submissions made by the parties, below, because even though the law will be changing, *Vivian* speaks powerfully to legal myths at issue.

The Mythical Adult Child in Divorce Law

In this section, I discuss the support of the so-called adult child in family law legislation. The myth of the adult disabled child is problematic from the standpoint of the legally putative “child” and mother's right to support. Christine Dobby¹²²⁹ points to the oddity of legislation that legally “childifies” adults as though they are minor children, simply because they are disabled.¹²³⁰ Had disability rights theorists examined single mothers' needs of support, as does Dobby, there might be a more robust rights perspective on this issue.¹²³¹

Pursuant to the federal *Divorce Act*, mothers may seek child support for “a child of the marriage”, who is, in fact, an adult.¹²³² Payment of child support to mothers of disabled adults poses troubling

¹²²⁶ It was moot because the matter was relitigated in *Coates supra* note 871 in which the caregiving mother this time prevailed in showing that her and her child's charter rights has been infringed by the statutory provision, and not moot because the disabled “child” Jamie Courtney had passed away, as was argued at the time the matter was being appealed. I refer to the other reason it was deemed moot below.

¹²²⁷ *Vivian* was similar to the *Coates* case (*supra* note 871) mentioned in Monsebraaten, “Brampton Mother”, *supra* note 1219; see also *J.M.S.*, *supra* note 15.

¹²²⁸ The father, as referenced in the trial decision submitted that “it is not clear to me why Nicole (the mother) is not working and not providing financial help to her own daughter. According to her financial statement she lives off government hand- outs such as CCTB and social assistance. If Jamie's circumstances could be better, it seems to me that Nicole bears the burden of that responsibility, since she provides no independent financial assistance to Jamie. Currently, the federal and provincial government, along with me, are the ones providing Jamie with the standard of living she enjoys”. *Vivian* (2010) which is the trial decision. *supra* note 1297.

¹²²⁹ Whose publication on this topic has been referenced by courts. Dobby, *supra* note 1161 at 57.

¹²³⁰ Childify is my own word. I do not feel infantilize is the correct word, though she uses the term. Dobby, *supra* note 1161.

¹²³¹ Family Alliance Ontario, a community living family organization intervened in the *Vivian* litigation to provide evidence in support of the claims for support. Their Intervenor's Factum, (23 August 2013), at paragraph 7, states that the financial support of both parents is integral to fostering the value of community-based supports.

¹²³² The Federal provision refers to teenagers over age 18 and older. *Divorce Act*, *supra* note ##, s 2(1).

questions about the autonomy of both single mothers and their dependent disabled adult offspring.¹²³³ A mother who seeks such support must demonstrate to the court that her “child” retains “child” status as disabled and is incapable of withdrawing from her charge, therefore child support eligible.¹²³⁴ It is understood in these cases that “the nature and amount of evidence will vary with the case.”¹²³⁵ Importantly, mothers must be prepared to deal with opposition to such claims, because fathers may (understandably or not) not want to pay ‘child’ support to an adult. The fact of mothers not wanting to perform care or needing to work is not a focus of such cases. Traditional male/female roles are at play, caregiver and breadwinner. As well, in family law, adult child support is the exception. The expectation in family law, as I note above, is that children will age out of child support, and that younger mothers will eventually become self-supporting, and are more able to do so as their children age.

Spousal support may not be an option for many mothers, as men with low income can show that they do not have the means to pay, while other men may litigate not to pay, or may choose not to pay irrespective of a court order or agreement to do so. As such, adult child support may take on greater significance to single sole supporting mothers with disabled children over age 18.

Case law reveals that some mothers are experiencing psychological violence as they battle myths embedded in law, as well as battling the disabled adult’s father in legal proceedings. This situation may be seen as an extension by reason of disability of Chesler’s notion that mothers are on trial in family law proceedings.¹²³⁶ This notion that mothers are harmed by extension should be borne in mind, for it is pivotal in my later arguments.

A family law case exemplifying the mythical autonomous adult child is that of the above noted *Vivian v Courtney*. This was an action brought under provincial family law legislation.¹²³⁷ It is an

¹²³³ See Dobby, *supra* note 1161 at 57. This is not done in a manner that supports their relational rights, on the contrary.

¹²³⁴ The adult’s eligibility ensures the mother’s eligibility.

¹²³⁵ Nicholas Bala, “Child Support for Adult Children: When Does Economic Childhood End?” (2008) Queen's University Faculty of Law Legal Studies Working Paper No. 08-01, at 10. The question of who is and who is not a child of the marriage is itself an area that is litigated. These legislative provisions look deceptively straightforward. In the setting of mothers trying to get some support for severely disabled children, they are a burden. There are cases going back to the 1980’s following deinstitutionalization of mothers bringing motions for interim support for adult children. For example, in the 1989 Ontario case, *Rakus*, *supra* note ##, a twenty-two-year-old, psychiatrically disabled “child” was held to be a child of the marriage pursuant to the *Divorce Act*. He was found to have no possibility of becoming self-supporting before the hearing of the petition and was found to be unable by reason of illness or disability to obtain the necessities of life, and therefore remained a child of the marriage.

¹²³⁶ See Chesler, *supra* note 23.

¹²³⁷ *Vivian v Courtney*, 2013 ONSC 5090 [*Vivian* (2013)], Endorsement of Justice Herman. At trial, Jamie’s medical evidence showed she had kidney failure, had undergone an unsuccessful kidney transplant and would be unlikely to get a second donor. She had an immune deficiency and had many infections. In response to the father’s allegation that his severely physically disabled and depressed now late daughter was not that ill, Madam Justice Curtis in the original trial, *Vivian v Courtney*, 2010 ONCJ 768 [*Vivian* (2010)] at para 17, opined “One does not have to be a physician to understand that Jamie is a seriously ill person. It is both surprising and concerning that the father wants to stop supporting this child.”

interesting case that involved a *Charter* rights claim.¹²³⁸ In it, the father brought a motion to end child support for his daughter, Jamie, citing that she had turned 18 and was not in school full-time. He also requested his “overpayments” in support be paid back.¹²³⁹ The mother sought to have his motion dismissed, arguing that Jamie was in school and was dependent due to her severe medical disabilities. The mother also sought an updated calculation of child support at the table amount, a continuation of child support and to have Jamie added to her father’s benefit plan.

The difficulty for the mother was that the Ontario *Family Law Act*, unlike the Federal *Divorce Act*, did not have a provision respecting the support of adult children with disabilities, so the mother had to hope the court would interpret her circumstances as fitting within the *FLA* provision for support.¹²⁴⁰

The father, opposing her claim, and relying on *Wilson v Wilson*, argued that his life-threateningly ill daughter was not pursuing her educational program with diligence.¹²⁴¹ Aside from the fact that this is an appalling argument, having examined the *Wilson* decision, which in turn, relied upon *Giess v Upper* for the presence of the diligence requirement,¹²⁴² it is apparent that neither case involved the narrow issue of time spent at school of an adult ‘child’ with a life-threatening illness such as Jamie Courtney had. Therefore, neither case was on point.¹²⁴³ This begs the question of why the father’s counsel tried to rely upon these other cases to make his arguments. That he did so was ableist. He treated Jamie as though she did not have a severe medical condition, and by extension, sought to undermine her caregiving mother’s claim. That the ableism was not called out highlights another challenge with support-seeking for disabled adults in family court files. Litigants can ‘get away with’ discriminatory tactics in the defense of claims,

¹²³⁸ Family Alliance Ontario intervened in this case, *supra* note ##.

¹²³⁹ Those payments made since Jamie turned 18 years of age.

¹²⁴⁰ By reason of a 2017 amendment, the *Family Law Act* RSO 1990 pursuant to section 31(c) now provides that an child support obligation exists where a child is unable by reason of illness, disability or other cause to withdraw from the charge of his or her parents. 2017, c. 34, Sched. 15, s. 1.

¹²⁴¹ *Wilson v Wilson* (2002), 117 ACWS (3d) 945 at para 19, 2002 CanLII 2824 (ONSC) [*Wilson*].

¹²⁴² *Giess v Upper* (1996), 28 RFL (4th) 460, [1996] OJ no 5600 (QL) (ONSC) [*Giess* cited to RFL].

¹²⁴³ Neither *Wilson* nor *Giess* dealt with a student with a severe disability. *Giess* dealt with a program offered through an alternative school for students struggling with personal or family issues, *ibid* at para 14. This is significant, because it demonstrates that those seeking not to pay support for their severely disabled teenagers who are in a program of education, in privatized settings, like Jason Vivian, may attempt to rely on case law that is not about disability in order to support their arguments. Again, disability is missing from private law, meaning ablest interpretations of the “child’s” educational circumstances may prevail. The fact that students with disabilities may take longer to move through a post-secondary education program than non-disabled students is a matter the Ontario Human Rights Tribunal dealt in relation to treatment under the Ontario Student Aid Program. See Carol Goar, “Deaf-Blind Woman Tests Canada’s Equality Guarantee” *Our Windsor* (29 July 2014) online: <http://www.thestar.com/opinion/commentary/2014/07/29/deafblind_woman_tests_canadas_equality_guarantee_goar.html>. ARCH Legal Clinic made submissions in response to Bob Rae, “Higher Expectations for Higher Education: A Discussion Paper” (Toronto: Queen’s Printer for Ontario, 2004), stating that “The student assistance framework is complex, insufficient, and does not consider the needs of students with disabilities.” This issue is being dealt with in public law, and family law courts need to address it too. See ARCH Disability Law Centre, “Submission to the Post-Secondary Education Review” (Toronto: Author, 2004) online: <<http://www.archdisabilitylaw.ca/sites/all/files/ARCH%20submission%20to%20PostSec%20Review%20-%20TEXT.txt>>.

which is something that the family law bar ought to examine. Thus the focus of arguments centered on evidence of Jamie's diligence as a student, not on her life threatening condition.

However in addition to claiming support under s 31 of the *FLA* on the basis of Jamie's student status, the mother and child, with the participation of an intervenor,¹²⁴⁴ argued that s 31 of the *FLA* discriminates against adult disabled children of unmarried parents contrary to s 15 of the *Canadian Charter of Rights and Freedoms*. They argued that the provision does not offer the same bases for bringing a claim for adult child support, as does the federal *Divorce Act*. Jamie¹²⁴⁵ herself argued that s 31 of the *FLA* was contrary to s 7 of the *Charter*.¹²⁴⁶

Justice Curtis was receptive to the presence of *Charter* concerns. Her Honour commented first on the moral aspects of the *FLA*, that aimed to shame and blame 'parents' whose children were born outside marriage,¹²⁴⁷ then opined that, these laws while directed at and defined by the parents' legal status, functioned to disadvantage blameless children. These laws she noted, could not survive the equality provisions of the *Charter of Rights and Freedoms*.¹²⁴⁸

Meanwhile, Jamie's father argued that "it is part of the provincial government's policy that the social safety net, including social services, are intended to be the primary mode of financial support for adult children that are disabled."¹²⁴⁹ *Vivian v Courtney* ended after the Attorney General argued that the *Charter* issue was moot, because the father had decided to pay support. The mother sought to have the issue of whether it was moot transferred to the Ontario Court of Appeal. However, Jamie, the adult child whose support was the subject of the lawsuit, died from her medical disabilities during the proceeding.

¹²⁴⁴ *Vivian* (2013), *supra* note 997, (Intervenor's Factum, Family Alliance Ontario as referenced in the case and accessed and reviewed).

¹²⁴⁵ Family Lawyer and law professor Shelley Kierstead, a member of my committee, acted for Jamie Courtney in *Vivian*.

¹²⁴⁶ Child support for those above the age of majority can be paid directly to the child.

¹²⁴⁷ See *Vivian* (2010), *supra* note 1237 at para 29.

¹²⁴⁸ See *ibid* at para 30.

¹²⁴⁹ *Vivian* (2010), *supra* note 1237 at para 11. At the same time as the *Vivian* litigation, Chris and Wilma Arthurs in Sarnia, Ontario were in the news concerning support for their 21-year-old daughter Emilia. Emilia had severe disabilities. In desperation, her parents left her at her respite placement, refusing to pick her up. They reported their plight at a news conference at Queen's Park, where they reported that Chris had six months to live, and reporting that the MCSS informed them that there would be no funding for Emilia's care. Meanwhile, 58-year-old Wilma's situation was that she would give Chris his injections, while Chris held Emilia's hands down. In this setting, her parents left her at her respite. Chris has since died, but Wilma is still in the media on this issue. See News Staff, "Ontario Couple Must Put Disabled Daughter in Nursing Home or Give up Custody", CityNews (12 October 2012) online: <<http://www.citynews.ca/2012/10/12/ont-couple-must-put-disabled-daughter-in-nursing-home-or-give-up-custody/>>; Laura Kane, "Disabled Daughter, 21, Surrendered by Family Likely Bound for Nursing Home", The Star (12 October 2012) online: <https://www.thestar.com/news/canada/2012/10/12/disabled_daughter_21_surrendered_by_family_likely_bound_for_nursing_home.html>; and Tyler Kula, "Ombudsman's Report into Special Needs was ignited in Sarnia", *Sarnia Observer* (25 August 2016) online: <<http://www.theobserver.ca/2016/08/25/ombudsmans-report-into-special-needs-facilities-was-ignited-in-sarnia>>.

The father's position too, was that his daughter's medical issues were irrelevant to a determination of child support, and that the only issue was whether Jamie was enrolled in school *full-time* in accordance with the *Act*.¹²⁵⁰ The medical issues, however, relate directly to Jamie's educational status and moreover to the ableist expectation of full-time study that exists in the legislative provision itself.¹²⁵¹ This feature has significance that reaches beyond the case.

Complex medical issues ought to feature prominently in support determinations, until the state starts to fulfill its support obligations to disabled adults, irrespective of whom they live with. In seeking to convince the court to terminate his support obligation, the father in *Vivian* agreed that the evidence showed that "extra income would help Jamie," but submitted that it was unclear to him why the mother "was not working and not providing financial help to her own daughter. According to her financial statement she lives off government hand-outs such as CCTB and social assistance."¹²⁵² He further submitted, "if Jamie's circumstances could be better, it seems to me that Nicole bears the burden of that responsibility, since she provides no independent financial assistance to Jamie," adding that "[c]urrently, the federal and provincial government, along with me, are the ones providing Jamie with the standard of living she enjoys."¹²⁵³

The father's submissions illustrate the astonishing characterization in court proceedings of caregiving mothers as having failed to provide support. On the father's appeal from Justice Curtis's enlightened order awarding 'child' support to the mother and Jamie, and contrary to the submissions made by the father, Justice Penny in the Ontario Superior Court of Justice opined, with reference to evidence of Jamie's palliative care physician, "The fact that Ms. Courtney is alive and able to live at home is a testament to her spirit, as well as the dedication, advocacy and hard work of her mother."¹²⁵⁴ Justice Penny added, "Parents of children of such chronic debilitating and ultimately fatal illnesses are performing a job that would occupy four or five employees in a long-term care facility."¹²⁵⁵

How is it that this information has not galvanized policy makers? On the one hand the Attorney-General in *Vivian* argued the *Charter* issue was moot when the father's appeal was dismissed.¹²⁵⁶ That may have influenced policy options. Then Jamie Courtney died. As noted above, what government does not do, is also policy. Not amending it during or immediately after *Vivian* was also policy. In not

¹²⁵⁰ The Ontario, *Family Law Act*, *supra* note 868 s 31(1) reads
Obligation of parent to support child:

31 (1) Every parent has an obligation to provide support for his or her unmarried child who is a minor or is enrolled in a full time program of education, to the extent that the parent is capable of doing so.

¹²⁵¹ Children of single mothers have less opportunity overall when only their mothers support them.

¹²⁵² *Vivian* (2010), *supra* note 1237 at para 74.

¹²⁵³ *Ibid.*

¹²⁵⁴ *Vivian* (2012), *supra* note 1237 at para 6.

¹²⁵⁵ *Ibid* at para 53.

¹²⁵⁶ *Vivian* 2013 ONSC 5090 *supra* note 997 at para 22.

addressing it, it is *de facto* policy that caregiving mothers not only provide onerous care at onerous levels, but may be denigrated as they do so. In her judgment on the motion, Justice Curtis opined as to hardship, but the father, who had been absent from Jamie's life for years, attacked the mother's credibility.¹²⁵⁷ In his post-trial endorsement on where the matter of the case should be continued, Justice Herman stated that Jamie had severe health problems and noted that according to the motion judge's reasons, the "father was not accepting the severity of (the child's) illness and had requested additional information about her health."¹²⁵⁸ The father was either in denial as to Jamie's condition or he was denying it as a litigation strategy.

This issue of *medical support* needs to be examined by the family law bar and by the state.¹²⁵⁹ Michael Tweyman, one of the lawyers who acted for the father in *Vivian*, states regarding support "that at a certain age, legal obligations ought to give way to moral ones."¹²⁶⁰ However, if a father is willing to litigate at the appellate level in order to obtain a court order relieving him of his obligations, it is clear he does not believe he has an obligation to support his disabled offspring, moral or legal.

Caregiving mothers seek to take the conversation about private disability support out of the moral realm and bring it into the realm of a legal right, where it belongs. As noted, the Attorney-General for Ontario in *Vivian* argued that the *Charter* issue raised by the mother, child, and intervenor became moot when the father's appeal of the award of child support made by Justice Curtis at trial had been abandoned. *Vivian* became moot in the opinion of the government when Jamie died. *Vivian v Courtney* remains a useful example of the fraught nature of caregiving mother litigation. One reason is it shows that challenging support law can become legally very complex. In *Vivian* the parties were arguing not only about the merits, but also about constitutionality and court jurisdiction.¹²⁶¹

¹²⁵⁷ One need only look at how the father's lawyer in *Vivian* (2010), *supra* note 1237, carefully crafts his words in order to construct the mother of his severely disabled daughter as lazy, as not pulling her weight, as getting a free ride and as being less than honest as to her motives and circumstances for not working outside of providing care to Jamie.

¹²⁵⁸ *Ibid* at para 3.

¹²⁵⁹ In *Dickie*, *supra* note 1165, the father, a surgeon, evaded support payments and court orders by ignoring and fleeing from them. These cases underscore the ways it is (a) harmful and (b) ineffective that the law require mothers to enforce their legal rights to support on a case-by-case basis. In *Dickie*, *supra* note 1165 (Factum for the Appellant at para 14), she submits that whether a court exercises its discretion or interprets a certain rule in such a way that fails to provide a remedy to the mother and children (including Dr. Dickie's daughter, Erin Dickie, who had learning with disabilities and who dropped out of high school because there was no money for her tutor) exacerbates the poverty of women, in particular, already marginalized women and not in compliance with *CEDAW*.

¹²⁶⁰ Michael Tweyman, "Court of Appeal Rules on ODSP Effect of Child Support for Adult Children" (17 June 2014) online: Tweyman Law Blog: <<http://tweymanlaw.com/new-site/court-of-appeal-rules-on-odsp-effect-on-child-support-for-adult-children/>>.

¹²⁶¹ In his Endorsement, Justice Herman summarized that "The respondent mother, Ms. Nicole Courtney, and the intervenor, the Family Alliance of Ontario, take the position that this matter should be transferred to the Court of Appeal. The Attorney-General's position is that it must be heard by the Divisional Court." *Vivian* (2013), *supra* note 997 at para 2.

Vivian illustrates not only a severely disabled person as the mythical adult *child* in family law, but it also challenges some of the mythology surrounding eventual financial independence of caregiving mothers of adults.¹²⁶² It highlights hardship on caregiving mothers such as Nicole Courtney. State support would alleviate hardship, however, as shown, such support lurks in its own realm of mythology revealed as it intersects with family law support.

Myth of Ready State Support

The myth of ready state support is so entrenched that it might well be described as the classic defense to a claim of private support for an adult disabled child. In *Vivian*, the father's position was, "that it is part of the provincial government's policy that the social safety net, including social services, are intended to be the primary mode of financial support for adult children that are disabled".¹²⁶³ This issue was also illustrated in the older case, *King v Sutherland*, in which the parties separated months after their severely disabled child was born.¹²⁶⁴ The 1986 divorce judgment was issued, along with an order for child support. In 1996, when support for the eldest child ended, the mother sought to vary the child support for their daughter, Rochelle. The father consented, on the stipulation that her support would end at age 21. Community Living Huronia (CLH) held out that a placement would be made available to Rochelle then, and the mother relied on that in her legal negotiations.¹²⁶⁵

However, the promised placement was not available when claimed. CLH had identified Rochelle as having "unique and exceptional needs which have not allowed for her residential placement ... and which continue to affect the ability to obtain community placement."¹²⁶⁶ When she turned 21, her father ended his support and sought clarification of his obligations. He was ordered to continue paying. Meanwhile, the Ministry's motion to be removed as a party was dismissed and it was ordered to pay a benefit to the mother. This was referred to by the judge as a "partnership approach" to support of adult disabled children.¹²⁶⁷ Subsequent motions were brought by the mother seeking support from the father, and by the Ministry, seeking to be removed as a party in the proceeding.

The child support payments of the father were upheld, however, the court order respecting the Ministry was overturned, with the determination that the court below lacked jurisdiction to make that order under the *Divorce Act*. Justice Strong noted that the mother had no income and that caregiving made

¹²⁶² Inside or outside marriage. See Thomson, *supra* note 338 at 86, for a perspective on lack of freedom and reinterpretation of it.

¹²⁶³ *Vivian* (2010), *supra* note 1237 at para 11.

¹²⁶⁴ Rochelle was described as having global delays for reasons "ranging from autism to Williams Syndrome." *King* (2004), *supra* note 1087 at para 2.

¹²⁶⁵ Arguably Ontario made an undertaking during the proceeding. All parties relied upon it.

¹²⁶⁶ *King* (2004), *supra* note 1087 at para 5.

¹²⁶⁷ He opined there are obligations on the state and on parents to support vulnerable members of society. *Ibid*, at para 26.

paid work impractical and further commented on her detachment from the labour force as factory worker, a result of caregiving, putting his finger on a larger issue. In his endorsement, he opined critically that the father saw his obligation as contractual only.¹²⁶⁸ The problem is that family law permits this interpretation by support payors¹²⁶⁹, and family law judges cannot bind government to their undertakings to provide care.¹²⁷⁰ In this case, the Judge, in his comments and in his effort to bind the province, challenged the myth of ready state support and when it was later held that he could not do this, he underscored the failure of state accountability to mothers and their severely disabled children. In so doing, Justice Strong exposed the myth of ready state support.

State supports for disabled adults are difficult to access, and it is surprising that this defense, based on a policy myth, is so routinely brought into play. It is also disturbing, as claimants must repeatedly introduce evidence to show how, in fact, the state is not providing support adequate to keep many mothers and disabled adults out of poverty. This is so, even though on their face, present levels of state assistance are consistent with *someone else* already supporting their disabled adult child, usually the mother.

My claim is illustrated in an Alberta case, *J.R.B. v C.F.B.* In this case, the father brought an application to terminate his child support for his 18-year-old, disabled son. He also sought to expunge his arrears in support for all his children. The mother's order for child support and the arrears in child support were dealt with in court by the Alberta Director of Maintenance and Enforcement.¹²⁷¹ The father argued

¹²⁶⁸ *Ibid* at para 7.

¹²⁶⁹ The issue of fathers and disability support was stark in *Coates v Watson*. The *Notice of Constitutional Question* in *Coates* involved an *Amicus Curiae*. *Amicus Curiae* means 'friend of the court', and their role is to advise. The *Amicus* were Michael Twyman and Gary Joseph. They advanced the position of Joshua Coate's father Wayne Marlon Watson, who sought not to pay support for his disabled adult child. With this aim in mind, the *Amicus* sought to keep out Intervenor evidence of Family Alliance Ontario that provided the social context of disability. The *Amicus* clarified that the issues to be resolved did not depend on the extent of Joshua's disability nor what his mother did to support him. They argued that the court was to take a decontextualized approach in its legal analysis, even though this is not what the Supreme Court of Canada has been advised is essential where equality rights are concerned. In short, they sought to have the determination of a family law support provision largely in place for mothers be de-linked from a particular form of mothering, that with complex care attached to it. This is what caregiving mothers have been up against. Justice Sullivan nevertheless contextualized his finding when he stated that "Disabled children of unmarried relationships, and their residential parents, most often mothers, face economic hardships and insecurity not visited upon those whose parents married. It is substantively discriminatory that children and residential parents have diminished access to financial resources as a result of the parents' marital status," *Coates supra* note 871 at para 97.

¹²⁷⁰ In *Krangle*, the parents of a boy with Down syndrome sued the physician who failed to offer them a prenatal test for costs of his support.

¹²⁷¹ The mother, although served, did not appear. The state appeared in the mother's stead as it has an interest in making fathers pay their child support, so that the state would not find itself in the position of support provider. *J.R.B.*, *supra* note 936 at para 17, refers to other similar cases, such as *Brown v Brown* (1996), 187 AR 156, 64 ACWS (3d) 840 (ACA) [*Brown* (ACA) cited to AR]. In *Brown* (ACA), involved a disabled child where the mother sought spousal support 18 years after the divorce, even though she had remarried and even though her second husband only worked part time so that he could help to provide care to the disabled child from his wife's first marriage. It also involved repayment of disability support money to the province. With regard to the spousal

that his son received income support from the province (Assured Income for the Severely Handicapped or AISH) and thus, child support from him was not required.¹²⁷²

In order to access some support for their disabled child, the mother dealt with two ministries, her husband and his lawyer. She contributed her home for her son to live in full-time, her business income to support him, and her physical and emotional support to ensure that his needs were met. She also provided her time and her advocacy, including being a party in this case.

The ‘private’ nature of family law proceedings was brought into question in this case when the judge addressed the standing of the Director of Enforcement as a “proper party” to the family law application to terminate support for the disabled youth and to deal with the arrears that had accumulated. The court held that the Director is “entitled to make any submissions available on the issue of entitlement to child support and cancellation of arrears. However, the Director has no subrogation standing in relation to AISH payments, and has no participation standing in relation to these payments.”¹²⁷³ This finding, set out under the subheading *Effect of Government Support Programs on Parental Support Responsibilities*, is that the father has no obligation.

The court held that, “A government program of assistance to severely handicapped adults although presumably providing for all basic needs - since some severely handicapped adults do not have independent means and some do not have extensive family support - cannot be sensitive enough to provide for legitimate extensions of basic needs.”¹²⁷⁴

The judge added that in this case, “there is no evidence to support any financial need beyond the amount paid by AISH,” concluding that “the AISH payment was ...adequate to provide full financial support *in his mother's home*.”¹²⁷⁵

That heavy maternal support is assumed in support schemes themselves, and left unvalued economically is legally problematic. It is a feature that undergirds unequal support obligations of men and of the state *vis-a-vis* caregiving mothers.

support, the father agreed he should pay support, but the parties disagreed with the quantum. The court found that the mother was economically disadvantaged having helped to put the husband through university, but also “due to devoting herself to caring [sic] the child and the resulting ill health to herself.” She had developed chronic fatigue syndrome and fibromyalgia. *Ibid* at para 14. The other issue, where the mother had not reported the \$75 a month she received in child support to AISH, she was ordered to repay. The court referred to the AISH as payments for “babysitting.” *Ibid* at para 7.

¹²⁷² This argument is seen repeatedly in family law cases for older teenagers (ages eighteen and nineteen) and older adults. The court found that “Mr. C.F.B.’s obligations to this child ceased when the child reached eighteen and he began to receive AISH. Therefore, that portion of the arrears which represents payments due in relation to this child after the child’s eighteenth birthday are cancelled.” *J.R.B.*, *supra* note 936 at para 22.

¹²⁷³ *Ibid* at para 12.

¹²⁷⁴ *Ibid* at para 21.

¹²⁷⁵ *Ibid*. My emphasis.

Reviewing other cases, the *J.R.B.* court raised a number of points. As just noted, the judge held that it is inconsistent with the purpose of the *FCSG*¹²⁷⁶ to reduce child support amounts where a child is in receipt of his or her parent's CPP disability pension child payments.¹²⁷⁷ This is because these guidelines do not provide for situations where a minor child has his own resources and are treated in family law as more than simple guidelines in practical reality.

However, the court distinguished the adult child, whose own resources it stated must be considered. The judge opined, "there comes a point when parents no longer have an obligation to support their children".¹²⁷⁸ He added that when children become severely disabled adults, "society says ... the parents of these adults have already done so much, that we accept it as our obligation to take over the main financial support of the handicapped adults in much the same way as we accept responsibility of providing social services for adults who are unemployed."¹²⁷⁹ This court held that "Mr. C.F.B.'s adult child receives a full AISH award. There is no evidence that the adult child requires additional financial support beyond the AISH award. Therefore, the father is not required to contribute to the support of the child of the marriage."¹²⁸⁰ Thus he was released from financial obligation towards his disabled child pursuant to the myth that the welfare state had taken over that obligation for him.

Meanwhile, the mother's forever and ongoing instrumental, social, economic and physical disability support disappears in this judgement. One is reminded of Sawyer's statement, that the words 'self-reliance' and 'independence' hide "relations of dependency and interdependency within the family."¹²⁸¹ Sawyer referred to the state rendering care invisible in "a vanishing trick", something she perceived as an attack on mothers' citizenship. The contributions of the mother in *J.R.B.* are disappeared in just this manner. It is curious that the court's opinion that by adulthood, "parents' have done so much already", does seem to apply to caregiving mothers, who are the very ones who have done so much. This is not uncommon, it would appear.¹²⁸²

¹²⁷⁶ FCSG refers to the Federal Child Support Guidelines, described above.

¹²⁷⁷ The court stated on the one hand that, "Arguing from first principles, one may have thought that if CPP is a replacement of income, and if a portion of that replacement income is sent direct to the income earner's children, the transfer of employment-type income to children is perhaps the equivalent of child support payments and could be taken into account to reduce the amount of child support otherwise payable." *Ibid* at para 14. The court referred to *Griffiths v Griffiths*, 1999 ABQB 193, 242 AR 186 [*Griffiths*], where the court held "that CPP payments to minor children should not be deducted from the payor parent's child support obligation..." *J.R.B.*, *supra* note 936 at para 15.

¹²⁷⁸ *J.R.B.* note 936 *supra* at para 16

¹²⁷⁹ *Ibid* at para 16.

¹²⁸⁰ *Ibid* at para 3.

¹²⁸¹ Sawyer, *supra* note 322 at 122.

¹²⁸² The court opines "When children become adults, and are permanently severely handicapped, surely our society says that this happens so relatively rarely, and that the parents of these adults have already done so much, that we accept that it is our obligation to take over the main financial support of these handicapped adults in much the same way that we accept the responsibility of providing social services for adults who are unemployed". *J.R.B.*, *supra* note 936 at para 16.

Jorgensen v Jorgensen is another case in which a mother sought support for an adult disabled child.¹²⁸³ Amy was a child from a prior marriage that took place in 1975. The natural father was deceased, thus although the case does not provide Amy's date of birth, she would have been in her late thirties at least, at the time of the decision. She is described as being developmentally and mentally disabled, having Angelman's Syndrome. Amy's stepfather agreed he had stood in *loco parentis* for 11 years. The judge noted that the mother had received services since Amy's birth and had required "considerable assistance."¹²⁸⁴ The judge opined, "While there are certainly cases that extend to [the] right to receive child support past the state of childhood where a dependency continues to exist, there are certain factors worthy of consideration."¹²⁸⁵ This judge considered relevant the mother's ability to work and her desired "lifestyle" to stay at home to care for the disabled woman, as funding would allow.¹²⁸⁶ We are not told much else about Amy, however the decision states that the mother received respite care and benefits for her, but that her benefits were reduced at the time of the case, which would be when Amy was becoming middle aged.¹²⁸⁷

Reviewing the mother's employment history, and calling it impressive, this judge describes her as cavalier about leaving paid work periodically, concluding that, "She is not unemployed as a result of her marriage nor is she in a state of dependency because of any tacit encouragement by her marital circumstances."¹²⁸⁸ Yet the facts of this case suggest the mother was under-employed because she had a disabled child in her first marriage, and because, even though in the second marriage, her husband took on the role of father, he did not take on the role of caregiver as did the mother. Justice Legere-Sers misses the state of dependency brought on by Mrs. Jorgensen being in the role of life-long caregiver to a disabled child.

In this case, one can see the charitization of Mrs. Jorgensen in family law.¹²⁸⁹ This is similar to what was seen in *Vivian* and in *J.R.B.* The legal treatment of mothers with disabled children as ordinary mothers by family courts is but one example of status misrecognition.¹²⁹⁰ Nancy Fraser states that misrecognition is a driver of conflicts, and conflict is what is seen in legal disputes that come about as a

¹²⁸³ *Jorgensen v Jorgensen*, 2003 NSSF 32 [*Jorgensen*].

¹²⁸⁴ *Ibid* at para 2

¹²⁸⁵ *Ibid*.

¹²⁸⁶ Madam Justice Legere-Sers's comment as to the mother's care provision being a matter of "lifestyle", make it seem as though she were taking time off.

¹²⁸⁷ *Ibid*

¹²⁸⁸ *Ibid* at para 3.

¹²⁸⁹ Other judges like Justice Curtis in *Vivian* have rendered strong opinions about this situation. However, they cannot change the *FLA* or the *Divorce Act* to reflect mother's contributions or needs, and even if they could, this still would not provide adequate support.

¹²⁹⁰ Nancy Fraser and Linda Gordon refer to registers of dependency when discussing stay at home mothers. It is clear from family law cases that caregiving motherhood qualifies as one of these. Fraser & Gordon, *supra* note 217 at 11.

result of the claims brought privately for support.¹²⁹¹ Until family law addresses the missing caregiving mother, such disputes will continue.

Other arguments have arisen in the course of litigation tied to myths about the state's role in supporting disabled adults. In *Steidinger v Morrell*,¹²⁹² the father sought to vary an order for child support and his support obligation to his 21-year-old severely disabled daughter, Christina, pursuant to the federal *Divorce Act*. The father relied on authorities suggesting that the principles of universal health care and the obligations of governments to provide social assistance meant that the obligation to support an adult disabled child lies with the state. In the alternative, he sought to establish that the table amount of child support was no longer "appropriate," as that term is used in s 3(2)(b) of the *Guidelines*. He argued that his support obligation should be reduced, commensurate with the amount that his daughter contributed to her own support from various provincial disability benefits.¹²⁹³ Not unlike the mother's position in *King*, the mother here claimed that the child support obligation should continue until their daughter was offered a placement in an independent living program. The mother, with whom Christina lived full-time, opposed his motion, arguing that her daughter was not self-sufficient, and would never be able to live independently even when enrolled in a Supported Living Program.¹²⁹⁴ The mother also put her own health problems into evidence. Thus, one might also interrogate the meaning of "independent" in the term independent living. The naming of such programs may place mothers at a disadvantage in family court where judges may not appreciate what is meant by the term, which is *supported* community living. In community living, mothers often still provide support, as seen in *Eve* and other legal cases I examine.

In making its deliberations, the court stated there was latitude for a range of child support awards. The court's disposition was that a material change in circumstances had occurred. However, the court held that just because the court "may" vary the order, does not necessarily mean it should. The court had found Christina turning 18 was a significant change in circumstances.¹²⁹⁵ However, it was not significant maternally.

¹²⁹¹ Nancy Fraser, "Rethinking Recognition", online: (2000) 3 New Left Review <<http://newleftreview.org/II/3/nancy-fraser-rethinking-recognition>>.

¹²⁹² *Steidinger v Morrell*, 2013 MBQB 143 [*Steidinger*].

¹²⁹³ *Ibid* at para 3. These were listed later in paragraphs 17 and 18 of the case as comprising tax credits, EIA benefits paid directly to Christina. A respite allowance paid to the mother and another \$40 a month Christina earned through a program. The mother and Christina were poor, and pooled money. The mother charged Christina \$285 per month as her full time primary caregiver. This "pooling" of monies troubles calculations in family law. Piecemeal disability benefits do not fit neatly into these cases.

¹²⁹⁴ *Steidinger*, *supra* note 1292 at para 3.

¹²⁹⁵ This was legally significant, as at this point Christina could receive \$10,900 in benefits from the province as an adult with a disability; it was differentially significant to her mother and father. Her mother continued on as she had when Christina was seventeen, supporting her in many different ways. For her father, it signaled he could return to court to ask to reduce or end his child support obligation. *Ibid* at para 31.

In fact, the materiality of this change in the setting of severe disability is contestable. The law permits the material change in circumstances arguments to be made by payors, since technically, state funding ‘options’ alter at this age and since it is the legal age of majority. However, although a modest disability income is offered by provinces, mothers describe ages 18 through 21 as timeframes when their children ‘fall off a cliff,’ in terms of support. There is little in the way of services in the community.¹²⁹⁶

The *Steidinger* court considered two recent cases in its deliberations, *Laing v Mahmoud* and *Briard v Briard*, and opted for the modified approach taken in the latter case, acknowledging that state support was insufficient and that child support should be increased because Christina was not in a position to withdraw from her mother’s charge.¹²⁹⁷ If the father were able to withdraw child support for his daughter, something the judge in this case stated would pose a hardship for the mother, then support obligations and costs associated with care would remain with his former wife, irrespective of what the state “ought” to do.

Again, a judge uses the word *hardship* and again, a judge challenged the myth of robust state support, finding that the caregiving mother is entitled to private monetary support. Yet the mother is in the position of having to rebut and defend against allegations by a parent who does not want to pay or pay more, which means that her so-called right to support is contingent on overcoming opposition to paying them. That is an onerous burden of care that mothers with disabled children should not have to endure.

The *Steidinger* decision focuses on the mother’s submissions that she “contributes disproportionately to Christina’s care and maintenance by contributing financially and by providing essential services, including daily supervision.”¹²⁹⁸ The court opined that in contrast, “Mr. Morrell spends little time with Christina and his only tangible support is the current monthly child support payment.”¹²⁹⁹ *Steidinger* is helpful, because in it, the court acknowledges the non-monetary support Ms. Steidinger provides. Justice Clearwater stated that the mother is “doing her best to support herself and the child and that she maintains the physical burden of Christina’s necessary care and supervision when Christina is not away from home and otherwise involved in the Program.”¹³⁰⁰ Justice Clearwater added, “As is the case

¹²⁹⁶ Aleksandra Sagan. Special-Needs Youth Face ‘Big “Abyss” After Leaving School’. CBC News, June 02 2015. Online< <http://www.cbc.ca/news/health/special-needs-youth-face-big-abyss-after-leaving-school-1.3095279>>.

¹²⁹⁷ *Laing v Mahmoud*, 2011 ONSC 4047 [Laing]; and *Briard v Briard*, 2010 BCSC 65, 81 RFL (6th) 223 [Briard]. In *Laing* the court held that the disabled adult child who lived with the mother was entitled to the table amount of support, even though in receipt of a provincial disability income support benefit. In *Briard*, the court found that a twenty-two year old adult with Down Syndrome who lived with the mother could not withdraw from her charge, based on \$10,900 annual income provided by the disability income support and a larger sum of child support was awarded. Judges in these cases found that the “society as a whole” notion of responsibility advanced in *Krangle* was not realizable and that private avenues of support had to be found.

¹²⁹⁸ *Steidinger*, *supra* note 1292 at para 4.

¹²⁹⁹ *Ibid*. In some cases then, the adult child’s contributed income is viewed as income to the mother, while in other cases, like *Ansell*, the court stated that the income is of/for the adult child and child support is to the mother.

¹³⁰⁰ *Steidinger*, *supra* note 1292 at para 14.

with Mr. Morrell, she appears to be meeting her current needs and obligations.”¹³⁰¹ I include this statement because submissions are made in such cases that mothers are shirking their obligations.¹³⁰²

After reviewing the law, Justice Clearwater held that the father had an obligation to pay child support stating, “which, in my opinion, should not obviate the importance of him doing his best to maintain some contact with her”.¹³⁰³ As noted in the literature, many mothers with severely disabled children provide care on their own. In spite of the judge’s acknowledgments, child support was awarded at less than half the table amount. The court did recognize that the amount of money the mother received from her disabled daughter was not in any way reflective of the “true cost” of the young woman’s support. However the judge also, rather curiously, opined that in her view the mother had “been able to structure her affairs so that almost all of the income she receives was non-taxable.”¹³⁰⁴ This implies that the mother had gotten away with something that put her at an unfair advantage. She reviewed the cases on point, one of which was *Briard v Briard*¹³⁰⁵ in which the father sought leave to appeal to the Supreme Court of Canada after he was ordered to pay child support, albeit slightly less than the table amount. That Court reduced his support obligation from \$578 plus his share of special expenses to \$500 a month, Leave was refused.¹³⁰⁶ Justice Clearwater acknowledged that the *FCSG* contemplated the variation with a proven material change in circumstances and she decided that Christina’s being in a support program comprised such a change. Based on that decision, she held that the continued application of the *Federal Child Support Guideline* amount was inequitable to the father, who ought not to have to pay the full amount for child support.¹³⁰⁷ The court stated it was “satisfied that the responsibility for Christina’s support should be shared by the parents and the province.”¹³⁰⁸

Halving the quantum of support calculated for a non-disabled child, and applying that to the support calculation of a highly dependent adult makes no sense. It is troubling that the calculation lacked crucial disability context, even as it purported to consider it. There is a gulf between the myth of robust state support and the reality of economic hardship, which this case was explored, with the court seeing past the myth to the harsh realities of under-supported care and a woman’s struggle to access money. Nevertheless care was undervalued and under recompensed. This is wrongheaded. Care has an economic value as well as a societal value.

¹³⁰¹ *Ibid.*

¹³⁰² See *Vivian* (2013), *supra* note 998.

¹³⁰³ *Steidinger*, *supra* note ## at para 35. In making his finding, Justice Clearwater considered Christine Dobby’s article, *supra* note ##, on the support of adult disabled children in family law, along with other authorities.

¹³⁰⁴ *Steidinger*, *supra*, note 1292 at para 32.

¹³⁰⁵ *Briard v Briard*, 2010 BCSC 65, 81 R.F.L. (6th) 223; *aff’d* 2010 BCCA 431, 94 R.F.L. (6th) 33; [2010] S.C.C.A. 435 (QL) (leave to appeal dismissed)

¹³⁰⁶ *Briard v Briard* 2010 S.C.C.A 435, (Q.L.).

¹³⁰⁷ *Steidinger*, *supra*, note 1292 at paras 33 and 34.

¹³⁰⁸ *Ibid* at para 42.

Above, I addressed the notion of co-parenting severely disabled children after separation as largely a myth. This discussion was in regard to levels of child support. As noted, support is not the only issue where the care of disabled children is involved. Where state supports are inadequate, caregiving mothers may also seek to enforce access of adult disabled ‘children’.

In the Nova Scotia case of *W.G.B. v C.D.R.*¹³⁰⁹ the mother applied to the court to vary access between the ‘child’ (21-year-old “T”), and her father. The decision notes that at the time of divorce, “the Court took into account the effect the burden of total child care placed on Mrs. W.G.B., including the fact that T required supervision almost on a 24-hour basis.”¹³¹⁰ ‘T’ is stated as being fifty-seventh on a waiting list for a space in a communal living residence,¹³¹¹ which is reminiscent of the situation in *King*, in Ontario.

The parents in *W.G.B.* did not want their daughter institutionalized, so they agreed with one another as to her being wait-listed for a community placement, and living with the mother. The father, however, was unwilling to provide care in the meantime.¹³¹² The mother, conscious of this unfairness, was not prepared to permit him to evade what she perceived as his care responsibilities. She sought to have him be available for more access by taking him to court. In the event that he refused to consent to this,¹³¹³ she sought an order that he pay the cost of respite. He refused to increase his access,¹³¹⁴ asking that the cost of his daughter’s respite care be provided out of funding the mother received from government. In other words, the father’s position was that the care for this child ought to be (i) subsidized by the state (ii) provided by the mother (iii) and later provided by the state. He took himself out of the caregiving/child support equation altogether. This is reflective of what I have referred to as ‘care-privilege’ in this setting. According to the facts, before separation the father “did not respond positively to Mrs. W.G.B.’s request to assist her by providing respite care/access visits, in taking a month in the summer, two weeks in the winter, and more extended contact with T in order to assist in and relieve the costs of caring for her.”¹³¹⁵

Justice Legere-Sers stated that both parents love and supported T but that T’s care was “emotionally and physically exhausting for both parents,” adding they did not find “the support they thought existed in the community through government sponsored community-based housing,” and that

¹³⁰⁹ *W.G.B. v C.D.R.*, 2004 NSSF 122, 228 NSR (2d) 269 [*W.G.B.*].

¹³¹⁰ *Ibid* at para 7.

¹³¹¹ *Ibid* at para 5.

¹³¹² USA litigation respecting conservatorship agreements post-divorce where there are adult children with severe disabilities.

¹³¹³ *W.G.B.*, *supra* note 1309, is an example of the way in which access is different in the setting of separation where there is a child with a severe disability.

¹³¹⁴ Olsen, “Market”, *supra* note 134 at 1536, refers to torts between persons in domestic relations and the matter of intra-familial tort immunity. This is a thought provoking area but beyond the scope of this dissertation.

¹³¹⁵ *W.G.B.*, *supra* note 1309 at para 14.

this placed stress on them, pitting them against one another “to provide for T.’s extensive needs as she enters her adult life, still unable to withdraw from depend[an]ce on her parents, community and government support.”¹³¹⁶ She also commented that the father was not emotionally equipped to provide care and that “the mother has no option if she wants her child to stay out of the adult protection environment with the current lack of placement options,” commenting that the mother was underemployed because of her role as a caregiver.¹³¹⁷ Again a judge draws attention to the responsibilities of the woman with full-time care and the economic ramifications of it. It is apparent in case after case that something is unjust about this.

The outcome is a decision promoting a “reasonable or equitable sharing of the burdens these parents face.”¹³¹⁸ The court did not seem to agree that it was fully the mother’s responsibility to provide and arrange care for T, or that the father’s obligations were those of optional assistance only given the context of the mutually agreed upon wait-list and avoidance of institutionalization. The myth of mothers as the natural caregivers did not hold sway in the *W.G.B.* court. The court ordered, (i) access costs to be paid by the father in the event he did not make himself available for regular periodic increased block access¹³¹⁹; (ii) if the father agrees to greater access, respite assistance will follow to his residence, otherwise the father will pay for respite care to cover the balance of hours not covered by respite care. Moreover, the father would be responsible for 4 weeks in the summer, one week in winter, and a week in each of Easter and Christmas vacation periods; (iii) the father will continue with his access schedule and, if unavailable, shall provide respite care also for this uncovered period.¹³²⁰

W.G.B. is helpful because the judge describes the state’s contributions, the limitations placed on the mother in terms of her ability to support herself while providing care, and further opines on the cost of respite.¹³²¹ She (I believe) coins the term “*access costs*” in the setting of the at-home severely disabled adult child. This importantly goes part of the way towards monetizing such care in family law. This in turn may help to alleviate the father’s care privilege. The court acknowledged that the father was not providing care at a fair level, *and that neither was the state*, with the end result that the mother was left to shoulder the burden of care, unjustly.¹³²² I conclude my discussion of select family law cases by stating that the term ‘child support’ itself contains myth. It provides the impression that children are actually supported by quanta set out in *FCSG*. The table amount ought to be renamed the “obligation to contribute to child support” to reflect more accurately what is taking place.

¹³¹⁶ *Ibid* at para 18.

¹³¹⁷ *Ibid* at para 30.

¹³¹⁸ *Ibid* at para 46.

¹³¹⁹ *Ibid* at para 42.

¹³²⁰ *Ibid* at para 44.

¹³²¹ *Ibid* at para 85.

¹³²² *Ibid* at para 46. This judge uses the word “burdens” in this legal context.

Those who have practiced family law can attest that many payors' table amount of support is the equivalent of the cost of a transit pass, or a transit pass and a winter coat. In fact, what many mothers receive is a meager contribution to the support *that mothers* actually provide. In the case of children with severe disabilities, this means not only under supported children, but unsupported caregiving. In the above discussions I have illustrated some myths that caregiving mothers confront when seeking support through family law. These myths interact with one another, making it difficult for mothers to demonstrate the support they provide and the support they require. It is apparent that at least some judges are aware of the injustices that present in societal and legal norms, whereby mothers are held responsible for complex care. Although family law all but ignores the high and varied cost of such care, such costs are addressed other civil law proceedings as a matter of course. It is to these cases that I now turn.

Other Civil Litigation

In this section I briefly discuss implications of Canadian childhood disability-care tort litigation. My aim is to demonstrate that courts have addressed costs in relation to complex care for severely disabled children in the context of an unwilling payor who, unlike most fathers in family court, have deep pockets. As noted in the methods section, I use case law as a source of information about disabled children and their mothers. My overall argument is that mothers with severely disabled children are grossly under-supported in public law. The private law support cases support this assertion.

In *Krangle*, parents with a disabled child brought a claim for negligence against a physician who failed to advise them about the availability of prenatal testing.¹³²³ The damages they sought were for the cost of future care. At trial, negligence was found and the damage award was made against the physician. The damage award was to pay for the support of their disabled son up to the age of nineteen. The trial judge determined it would be in the best interests of the child to live in a group home at his age of majority, and all parties agreed.¹³²⁴ The court further stated that the state support arrangement after the age of 19 would be provincially funded.¹³²⁵ However, the trial judge awarded the parents an additional \$80,000 in the event that the provincial scheme was not in place. Thus the trial judge's ruling made it clear that the court expected the state to provide adult disability support and residential community care, not the parents. Subsequent to the decision by the trial judge, the provincial government amended that

¹³²³ They stated had it been offered, and their child's condition/disability detected, they would have terminated the pregnancy. While discussion of the selective termination of disabled fetuses has been addressed in critical disability analyses, is beyond scope in this discussion.

¹³²⁴ *Krangle*, *supra* note 765 at para 1.

¹³²⁵ The Supreme Court of Canada decision provides little information on the nature of the funded community living arrangement for the disabled boy it assumed would be in place at his age of majority. *Krangle* was a British Columbia case and it should be borne in mind that Joyce Dassonville, who brought claims against the government of Nova Scotia in 2002, whose case was discussed in Chapter Six, later brought claims against British Columbia in respect of care for her daughter. British Columbia was also the province where the *Auton* case originated.

province's *Family Relations Act (FLA)*, redefining the word "child".¹³²⁶ The amended section stated that "[e]ach parent of a child is responsible and liable" for the child's support. Section 87 defined "child" as including an adult over age 19 who "is unable, because of illness, disability or other cause, to withdraw from their charge or to obtain the necessities of life"¹³²⁷ In so doing the province exposed the myth of the state's shared role in supporting disabled adults, discussed previously. It also demonstrated, I feel importantly, that legislation can be changed readily when political will is there. This was an example of state retrenchment from the funding and provision of disability care and support. The decision was appealed by the physician. A legal question that arose was whether the above noted amendment of the family law legislation rendered the parents liable for the support of their child under the new provision *after* he reached age nineteen. Justice Mackenzie for the British Columbia Court of Appeal held "s.88 (1) of the *FRA* imposed a parental obligation to care for disabled adult children. The philosophy underlying the *Act* was that the parents' obligation to support adult disabled children preceded that of the state."¹³²⁸ Thus the extent of support obligations was far from clear among the judiciary. The trial judge saw a clear role for the state but the court of appeal judge saw the parents as primarily obligated in law. Given the negligence claim of the parents was for the cost of disability care, the courts had to grapple with the wobbly interplay between quantum of damages and the availability or unavailability of future state support. The other issue was the pushing by the state of disability care into the private domain. In such case the boy's mother would most likely be the one to have to take on disability care. On appeal to the Supreme Court of Canada, the issue was whether the parents could recover damages from the physician for their disabled child's *adult* care (after he turned 19) in light of the amendment to the family law provision. The parents argued that if the amendment to that province's family law legislation made them responsible for the child's support after age nineteen, and if the province made a claim against them respecting the cost of his placement in a group home, then the award of damages for their adult child care ought to be larger than was stipulated at trial. The physician appealed further, seeking to have the initial award reinstated. He did this because the initial medical negligence award against him limited the amount of damages to parents to cover the cost of future care.¹³²⁹ He prevailed when the Supreme Court of Canada restored the original award amount. The Supreme Court of Canada held that the Court of Appeal

¹³²⁶ *Family Relations Act*, RSBC 1996, c 128, s 1(1).

¹³²⁷ *Krangle*, *supra* note 765 at para 6.

¹³²⁸ *Ibid* at para 9.

¹³²⁹ As the Supreme Court of Canada stated, the Court of Appeal "rejected the argument that liability must be based on the legislative scheme in place at the time of trial, and that the amendments to the *Family Relations Act* could not be considered. It held that the damages at issue involved future costs, making it unnecessary to consider the Act's retrospective and retroactive effect. The change in the legislation was a relevant fact before the court. If the change in legislation had reduced the parents' liability for cost of future care, it could not seriously be contended that Dr. Morrill would not be entitled to the benefit of the future cost reduction. The same must hold where the legislation increased those costs." *ibid* at para 12.

had erred in finding that the change to the *Family Relations Act* would result in the imposition of an obligation on the Krangles to support Mervyn when an adult, with its reasoning being that the costs of the group home would be *fully* met the British Columbia government and that the family law amendment thus did not change anything decided at trial.¹³³⁰

A curious thing about the *Krangle* case is the trial judge's conclusion that there was a 95 % chance that the scheme would remain the same, thus justifying reducing the damages awarded by this substantial contingency.¹³³¹ If ever there was something one ought not to take judicial notice of, it is the inconsistency of child disability policy over the long or even short term, for it so frequently changes as was discussed in Chapter five. This case tells us there exists a state obligation towards the support of adults with disabilities. However, it also tells us that when parents succeed in bringing attention to the state's obligation to provide care, the state might legislate against that eventuality.¹³³² This private law myth of ready state support is similar to the public law myth of state largesse. The political myth being that the Canadian welfare state supports those in need of it, the reality however being that as soon as state support appears on the horizon, steps are taken to pull it back.¹³³³

Compensation for future care-performance, as a legal issue, has been raised by scholars. They note that the law has yet to address the value of maternal care performance.¹³³⁴ Feldthusen argues for example that mothers ought to be able to get damage awards for care performance in certain negligence cases that implicate care. He distinguishes between the ramifications of care performance on the one hand

¹³³⁰ *Krangle*, *supra*, note 765, at para 41.

¹³³¹ *Krangle*, *supra* note 765 at para 5.

¹³³² *Spencer v Ministry of Health*, [2016] NZHC 1650 [*Spencer*], was a reference by the New Zealand Human Rights Tribunal, to the New Zealand High Court. In *Spencer*, an older caregiving mother had brought a claim of discrimination in the Human Rights Tribunal, and prevailed. However, the Ministry of Health questioned whether the Tribunal ever had jurisdiction to hear her claim. The facts of the case are that Spencer and her husband were separated in 1990 and she then stopped working in the family business, and became their son's caregiver. Paul had never lived independently and his mother has always cared for him. Spencer received welfare during these decades, and recently accessed her pension. Her claim pertained to the care she had provided to Paul from January 2001 to May 2013, during which the Ministry had declined to pay for her services to her son, under its home care policies. They declined because her status as his mother, which disqualified her from receiving payment. The High Court decision stated that since 2014, she was paid by the Ministry of Health under its family care policy. She was being paid minimum wage for 29.5 hours of personal care and household management a week, pursuant to the *New Zealand Public Health and Disability Amendment Act*, 2013/22. However, in the new legislation, a clause prevents future claims of discrimination. There are two reasons for mentioning this case. The first is that it provides an example of status misrecognition of caregiving mother's work. Spencer however was awarded \$207,000 in back pay. Second, this case puts a dollar value on disability care provided by mothers to disabled adults. This acknowledges caregiving mother's right to support. The 2014 legislation, which barred further such lawsuits was passed "under urgency" and without public consultation. This is similar to what happens in the provinces. See "Editorial: Disability Bill Demonstrates Abuse of Due Process", *New Zealand Herald* online: <http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=10884930>.

¹³³³ What Gilmour refers to as the state *redrawing* the line pertaining to its role. See Gilmour, *supra* note 36.

¹³³⁴ See for instance Bruce Feldthusen, "Suppressing Damages in Involuntary Parenthood Actions: Contorting Tort Law, Denying Reproductive Freedom and Discriminating Against Mothers" (2014) 29 Can J Fam L 11 [Feldthusen, "Suppressing"].

and the existence of the child on the other. This way, the value and importance of care is not conflated with the value and importance of the child (irrespective of disability status) who requires care. He clarifies a crucial conflation in stating that, “What is in issue is the right to recover damages for the cost raising a child. What is not in issue is the value of the child. The point is not whether the child was born with a disability. The point is not whether the child has a formally recognized disability. The point is what it will cost to provide the requisite level of care for the child.”¹³³⁵ This strand of scholarship is here mentioned because it calls attention to a problem in the area of family law too, as an under-examined domain in civil law, where mothers with care of severely disabled children are concerned.

Conclusion

My critique of efforts undertaken in private law by mothers to access support reveals a number of difficulties in this area, as well. I described how the policy approach that considers family law’s child support provisions as being suitable or adequate support for the severely disabled child is untenable.¹³³⁶ My critique further shows that private law does not and cannot ‘solve’ the support needs of mothers with severely disabled children. On the contrary, it often adds to their burdens of care, as I have described that term.¹³³⁷ It does so in part through the use of a series of myths brought into play to unseat mother’s claims. However, as cases reviewed suggest, caregiving mothers do not lack consciousness about these points. On the contrary, the cases show that mothers with severely disabled children seek to challenge, expose, resist and change the features of support law that denies them support. Their ongoing project however is met with considerable state and private opposition, as seen in the civil litigation discussed in this chapter.

¹³³⁵ *Ibid* at 35.

¹³³⁶ Severely disabled children and their caregiving mother’s concerns were evidently not factored in when meetings were held to discuss support,

¹³³⁷ I reiterate here that many of the burdens of care that negatively affect caregiving mothers, also negatively affect disabled children. Thus, disabled children suffer as a result of unaddressed maternal care burdens.

CHAPTER EIGHT: Conclusion - Towards Legal Rights to Support For Mothers with Severely Disabled Children

Introduction

In this concluding chapter, I begin with a statement of my thesis. First I reiterate my research questions, with a brief comment on what I mean when I refer to ‘rights.’ I then précis the methods I used in examining caregiving mothers’ litigation, doing so in the context of the scholarly work that informed my project. I follow with a discussion of conclusions to be drawn from my analysis when caregiving mothers bring claims for support or defend against its termination. Finally I identify what I see as the most promising approach that caregiving mothers might take to advance their legal right to support, given what the research and legal cases reveal about their lives and the lives of their severely disabled children.

Statement of Thesis

My dissertation is an inquiry into the legal rights to support of Canadian mothers with severely disabled children. I asked what their legal rights to support are and what they should they be. I further asked what are the legal rights of children with disabilities to state support and what should they be. In addition, I asked how the legal rights of the severely disabled child ‘fit’ with the legal rights of mothers to public support within existing frameworks.

Approach Taken

To carry out my research I undertook a literature review examining scholarly work about mothers. In addition, I examined critical disability literature, feminist legal literature, other critical theory literature, literature on research methodology, as well as scholarly work in the area of care. I examined political science and economic literature; and the doctoral work of others who had researched in the area of mothers with disabled children. I reviewed media reports, statutes and legal cases. I reviewed government policy reports and private sector policy publications, as well as support policy provisions. Central to my research, I also examined legal cases in which mothers with disabled children sought support, through private and public law.

The inclusion of a policy analysis in Chapter Five in my dissertation sheds additional light on how mothers with severely disabled children are situated in support law. A great deal of disability support is provided to mothers across Canada through policy mechanisms, such as directives or regulations. Some of the litigation I examined involved discussions about support policy of different kinds.

My project thus entailed a review of relevant literature and law, rather than an empirical collection of data through personal interviews. My particular research focus was on what was taking place when mothers brought legal claims or otherwise articulated rights claims. Mothers' voices come through in the litigation.

I recognized early in my research that interviewing government officials was unlikely to be helpful. I met with a senior bureaucrat in the Ministry of Children and Youth Services several years ago for an informational interview. She advised me the areas I was inquiring about could not be discussed. In fact, I was able to achieve my research aims without conducting any interviews, for the following reasons. (1) I was provided with important and hard to access government policy documents and reports by a policy advisor from the private sector that contained the information I required. (2) I could rely upon government's own published research. (3) I also sought out policy information both from legal cases and the media, as well as government policy initiatives set up over a span of time showing the government's position on the issues of support. (4) Government positions and submissions in legal cases provided information about policy. Together this policy information, along with the legal research, gave me the needed background to address my research questions.

Nature of Rights Examined

At the outset of my thesis, I described what I mean by the basis for legal rights of caregiving mothers. In summary these are, i) entitlements in statutes, ii) an ability to apply for discretionary benefits in public law/policy iii) rights claims where no 'caregiver-mother specific' legal support right exists, iii) international human rights law, and iv) theory of relational rights. I also discuss disabled children's rights.¹³³⁸ Disabled children's rights are expressed and realized differently than are their mothers' support rights. However, their legal rights to support are realized through their mothers, as it is their mothers who advocate and litigate on their behalf. Their rights are also addressed in the dissertation in the context of international human rights instruments.

My research into the various legal rights of mothers with severely disabled children was conducted from within two connected conceptual frameworks, discussed next.

Theoretical and Methodological Approach

The conceptual frameworks I used were feminist standpoint theory and theory of critical consciousness. These provided me with analytical tools within which to examine the legal cases, policy and scholarly

¹³³⁸ They are realized based on the principle 'best interests of the child,' and through the *parens patriae* jurisdiction of the courts, as well as by other means, such as domestic and international law. They are largely *advanced* however by caregiving mothers.

literature as well as media reports. For example, I drew from the construct of societal myth proposed by the theory of critical consciousness and used the notion of legal myth to analyze what was taking place in legal cases. I found this to be a useful tool of analysis, and in fact one that helped me to identify subtle features in policy, legislation and decisions. As noted in Chapter Two, feminist standpoint theory is also a critical theory, one which concerns the production of knowledge and the workings of power. It advances the view that one's standpoint (or social location) provides a unique means to access insights in knowledge and power relations. This theory is noted to work well in tandem with the theory of critical consciousness, since one's standpoint is considered to be a key aspect in the development of critical consciousness.

These frameworks allowed me to see and show how caregiving mothers engaged in litigation were seeking to meet personal support needs. In their litigation they were also geared towards bringing about social and legal change for them and their children, yet they faced many and often unsurmountable barriers in so doing. The literature I reviewed supported this line of inquiry, as did interviews caregiving mothers gave to the press regarding the state supports they had received over a lengthy period of time.

Within this framework, I adopted feminist legal methods to analyze material. As described in Chapter Two, feminist legal methodologist, Elizabeth Bartlett, advanced the uses of multiple approaches in the analysis of law as a patriarchal institution. Her approach permits women's lives to become visible in law. In my research I paid attention to the *text* of cases. This method was shown to be effective in analyzing the claims and submissions made in cases I reviewed, the opinions and *obiter dicta* of courts, what was not said in cases, including in precedential cases to which courts referred, as well as the decisions rendered. Omissions also provided valuable information about gender and care.

In addition to the evidence marshaled by various parties, I reviewed what else was and was not going on in these support cases. This idea to look at what was *not* happening was drawn from a scholarly article by Phinney. He critiqued the decision in a support claim about a mother's missing rights in a case ostensibly concerning them. I thus discussed erasures and omissions in the cases I used. Some of these I characterized as legal myths, perpetuating legal fictions and unjust outcomes responsabilizing mothers for care. It became apparent to me that these fictions and outcomes buttressed what was not only a patriarchal version of motherhood, but also an ableist version of it. In terms of what else was taking place, the litigation showed that childhood disability was not accommodated, and/or not adequately addressed in support law.

The Prior Body of Literature and My Contributions to It

Since my project was interdisciplinary, I referred to scholars whose work was from diverse disciplines in my literature review. Some of those who were influential were Adrienne Rich, Jonathan Herring, Nancy

Fraser, Kiran Manhas, Sarah Green, Patricia McKeever, Joan Gilmour, Jo Bridgeman, and Maritza Montera (whose work informed my conceptual framework). Also influential were Dick Sobsey and Colin Barnes. Others not referred to in this reflection were important in analyzing the legal problems examined. Scholarship in social reproduction, poverty, neo-liberalism and the political era that followed it, referred to as The Third Way, all contributed.

I first mention Adrienne Rich. Her insight was a starting point in contemplating my research questions. Rich wrote *Of Woman Born*, in 1976.¹³³⁹ In it, she characterizes motherhood as a sociological and historical construct and importantly, as an institution. Her idea was radical at the time it was articulated, and stood in opposition to the entrenched notion that motherhood is a ‘natural’ state, biologically defined as a woman having had a child and becoming a mother. Rich saw that the status of mother is viewed by society as being a woman’s destiny. This she describes as patriarchal mythology.

Rich’s juxtaposition of institutional versus natural motherhood was useful. The present daunting circumstances of caregiving mothers in no way appear ‘natural’ in the legal cases I examined. Rather, their circumstances of grossly insufficient supports and needing to constantly contest meager support offerings appear more as part of a highly gendered political-economic plan.

As seen in my thesis, severely disabled children have neither corresponded with the children envisaged in patriarchal motherhood or in the dominant culture. Related to that, the demands of such care, which comprise the subjective and objective burdens described by Green,¹³⁴⁰ result in caregiving mothers ‘failing’ to meet the expectations of motherhood as an institution. Accepting Rich’s conceptualization of motherhood as a patriarchal institution, the structures around it, *such as law* and policy, are also patriarchal. Rarely can one claim that support-seeking caregiving mothers had power in the legal cases I examined. And rarely were fathers seeking support. Only two cases involved fathers seeking support, one in the context of child welfare disability support and the other in the context of a severely disabled mother who could not provide care. Their claims were entirely atypical.

I showed through an analysis of a diverse body of litigation, that the structures reinforcing the institutions of motherhood are also ableist. This legal analysis was bolstered by the opinions of both a provincial and a federal court judge, who, in their dissenting judgments commented on the law’s failure to account for the contribution of mothers with disabled children.

My thesis thus expands upon Rich’s insights regarding the institution of motherhood. The difficulty and /or inability of caregiving mothers to access needed supports, as seen in the legal cases, and reports about the cases I examine, reveal the inherent barriers, exclusions and omissions of caregiving mothers’ circumstances within the structures that make up motherhood as an institution. These revelations

¹³³⁹ Adrienne Rich, *Of Woman Born: Experience and Institution* (New York: Norton, 1995) at 42 [Rich, *Of Woman Born*]. *supra* note 232.

¹³⁴⁰ Green, *supra*, note 461 at 471.

show that supports needed are of a different order than the normative supports anticipated by patriarchal motherhood. Worthy of note is that caregiving mothers are forced to answer to not one but two sets of expectations in accessing supports, those of patriarchy and those of ableism.

These two ideologies interact to oppress caregiving mothers who assert a legal right to support. The cases I examined also demonstrate that caregiving mothers resist and contest the power of this “double-whammy” status quo. Cases also suggest that caregiving mothers who seek supports seek status recognition *as unique mothers*, i.e., those who provide *maternally* complex forms (plural) of care. And they strive to end their exclusion from an alternately unresponsive and/or punitive institution. One can see then that Rich’s notion has both contributed to and been built upon in my work.

Patricia McKeever is another scholar whose work has been highlighted in my literature review, as well as in other chapters. Her early work described feminine caregiving as a discourse that undergirds societal expectations of maternal performance of complex care for children. The discourse posits that mothers are the natural and optimal caregivers for children, and her work showed that to be true for even children with severe medical disabilities who were medically complex and technology dependent. Her work calls attention to the ways in which such mothers’ care is unique and also the ways they struggle with it. As such, her research supports Rich’s observations, as it shows mothers performing the difficult care for their medically complex children, and doing so within a powerful (then) male dominated profession with strong expectations of maternal compliance. In co-authored work McKeever examines shortfalls in state responses to the need for support in the areas of home nursing care to mothers with medically complex children. These authors concluded there are *ethical* problems in the way government provides home care for medically complex children in that responsibility for difficult medical care was shifted from the state to the home, with the cost of this shift carried disproportionately by women.

The legal cases I examined, as well as descriptions of other kinds of advocacy for caregiving mothers (such as reporting a care crisis to the provincial Ombudsman), support McKeever’s conclusions in her early research¹³⁴¹ that they are a unique group of mothers. Her project allowed me to conceptualize *maternally* complex care, as a label that helps to recognize medically complex caregiving *mothers*. While, as McKeever describes, caregiving mothers orient themselves in particular ways to medical professionals to obtain optimal care, I point out that caregiving mothers *orient* themselves to disputes to obtain basic supports. I retained a curiosity in their orientation throughout my project, as it suggested their awareness of support regimes as being oppositional rather than as supportive and cooperative.

My project continues with what McKeever observed, which is that mothers struggle, because they require greater levels of publicly funded nursing and other care than is made available. Judges in several legal cases I examined raise the issue of the impacts of care performance on mothers’ health, some relying

¹³⁴¹ McKeever *supra* note 320; McKeever and Miller, *supra* note 541.

on medical reports. Many mothers in the legal cases I examined describe health problems. Current care policies are described as being ethically problematic by McKeever; my thesis draws attention to how the ethical issues she and her co-authors raise, are also legally problematic.

I also reviewed Joan Gilmour's work, which predicted problems would arise as the state continued to redraw the line in its increasing privatization of healthcare. She also predicted that as it did so, demands on women would increase. She commented that the state's expectation that women will provide care without pay would carry an onerous social and emotional toll. History has proven her right, as the cases and research I undertook establish. Gilmour's comments align with those of McKeever, as well as those of Armstrong and Armstrong, whose work I do not reiterate here, but which likewise expressed concern about provincial withdrawal from a variety of forms of care provision, including the care that mothers now perform. The latter authors comment that state withdrawal from care poses problems. These are significant for mothers with severely disabled children, who may end up with little in the way of money, outside interests, social networks and resources, because their lives are dominated by complex care, often in combination with the other 'child care' obligations they juggle. Unless these mothers have significant other/outside financial supports, such as reliably paid, very long-term, consistently high levels of child support or a partner with an extremely high income (both rare and precarious) the Canadian state's withdrawal from care is harmful to caregiving mothers.

My examinations of the literature, policy reports, and cases concerning care for severely disabled children, together support Gilmour's prediction. Caregiving mothers in their claims and in their media interviews present not only gaps in care, but also evidence of the catastrophic personal impacts of the demands of the forms of care they are engaged in when they are so inadequately supported.

I also highlighted the work of Sarah Green, in particular, her article challenging ideas about what is burdensome to caregiving mothers, and what the impact of such burdens is.¹³⁴² Her work has contributed greatly to my understanding of the gendered nature of care burdens in the setting of maternally complex care for severely disabled children.

Green innovatively introduces the notion of subjective and objective burdens of care as a means to distinguish between the kinds of care challenges caregiving mothers face. Objective burdens include stress related to the care of the child, financial concerns in providing care, the lower ability of mothers to pursue friendships, and the high energy that must be spent seeking services, amongst others. She points out that other literature has focussed on maternal distress, which she classifies as subjective burden. The distinctions she draws help to clarify some of the fault lines in state support.

Green's work makes a significant contribution to our understanding, because it challenges claims emanating from prominent critical disability theorists. Some of these theorists reject care burdens as

¹³⁴² Green, *supra* note 461.

artifacts of an ableist society. This eschewing of mothers' burdens translates into the characterization of caregiving mothers as people who 'complain' about care, and who narcissistically valorize their own caregiving over those for whom they care, as I discussed earlier. Green's theory challenges critical disability theory further, by proposing some of these burdens as features of care that are *injurious*. One aspect, as Green notes, is that caregiving mothers are 'exhausted', and she challenges the reader to accept that as 'normal' or as being just.

My thesis extends Green's thoughts on burdens of care and mothers with disabled children. Legal cases I examine add to an understanding of an array of care burdens and their impact in diverse domains, such that burdens of care seen in my legal research threaten the ability of a mother to retain custody of her severely disabled child. Green's idea of objective burdens allowed me to posit *an extension* of care burdens to include a series of maternal losses incurred as a result of having been assigned the role of 'caregiving mother'. These include pension loss, salary and other financial loss, child loss/loss of maternal status, career loss, and other such features of complex care exposed in the legal cases mothers bring to courts and tribunals.

Green's ideas permitted me to challenge interpretations of care burdens in legal cases that were hostile to caregiving mothers and dismissive and disparaging of care burdens as a concept when it is applied to the care of severely disabled children.

Two prominent critical disability scholars whose work was influential in my thesis are Colin Barnes and Dick Sobsey. Barnes has written an important text, along with Geoff Mercer, about how best to conduct disability research. The text addressed issues about whose research disability research was, and the need to involve disabled people in research about them. This text reminded me at all times to factor my lived experience as a medically disabled mother in my research and my analyses. It also reminded me to call upon my relational knowledge of mothering children with a range of mild, moderate and severe disabilities.

In one of Barnes' other works, he waded into the area of rights and the disabled child, while critiquing a UK charity poster. Barnes' critique draws attention to societal exclusion, which permits the support of disabled children to fall outside the law. However, Barnes omits any mention of the care, work and advocacy of mothers of children with severe disabilities. Nor does he consider mothers in his critique of the charity model of disability. His commentary underscored for me that even when the rights of a disabled baby are under discussion, its mother's rights are erased.

My thesis further interrogates what Barnes describes, that disability care by mothers is largely outside the law. The one in whose arms the disabled baby is sitting in the charity poster, and by whom the baby is instrumentally supported, is the one who has problems realizing her rights and her child's rights – the mother. Although Barnes offers a critique of the charity model in the context of disability, he fails to

see the charity-like status of the disability care-occupied mother. Her care is not remunerated, as Gilmour describes in her work. And as Herring notes, it is assumed that she will provide it. In my thesis, this reality was at the heart of caregiving mothers' lack of status recognition, the latter being a concept drawn from the work of a feminist critical theorist, Nancy Fraser whose work was also influential.

The social model of disability, first described in the literature by Mike Oliver, allowed Barnes to articulate the lack of support rights of the child *as a disabled person*. The disabling social relations he identifies failed, however, to provide him with insight into the caregiving mother's *related* exclusion from law. This is one of the issues I grapple with in my thesis. Barnes, like some other scholars in the field of critical disability studies, does not appear to be aware of, or particularly concerned with, caregiving mothers' rights or the relationship of a mother and her disabled child. Thus my work pinpoints an ideological gap, which is a contribution to our understanding of unrealized support rights. My legal analyses reveal that the best interests of severely disabled children are not only linked to, but in many respects *are contingent upon* their mothers' legal right to support. Where mothers' rights fail, so too may those of their severely disabled children. Barnes' critique of the poster provided me with a template on which to sketch my ideas about maternal disability care being taken for granted in critical disability discourse.

Turning to another influential critical disability scholar, I assess the contribution of Dick Sobsey. His work has focused on the right of disabled children to be included, and their right to be safe. He is to be lauded for his cataloging of violations against disabled children, and for raising awareness about the important issue that they are bullied and murdered more often than non-disabled children.

Sobsey, however, is both critical and dismissive in his stance towards caregiving mothers in crisis, and those caregiving mothers who have claimed that they require more state support. Their claims are ideologically counter to how he envisions life with disability. Where desperate mothers have declared they are in crisis, he has rejoined that there has been far 'too much stress on stress.'

Sobsey's work encouraged me to be careful to explain that the burdens of care that mothers describe in legal cases do not confer a status of 'burdensome' on their disabled children. Thus I was mindful to avoid this conflation when discussing burdens of care in the setting of support seeking mothers. The burdens have to do with the care *and not the disabled child*. Recognizing the need to untie this knot describes one of Sobsey's larger contributions to my project. His denunciation¹³⁴³ and/or dismissal of struggles by mothers drew my attention to his work.¹³⁴⁴ His strong positioning against robust state supports is a diminution of its importance. One study I examined advances the position that 'good

¹³⁴³ Sobsey *supra* note 540.

¹³⁴⁴ McConnell et al. *supra* note 531 at 89.

copers¹³⁴⁵ are those who demonstrated “satisfactory family adjustment ... and child wellbeing”. Good-copers were pre-selected to participate in a study purporting to show the transformational benefits disabled children confer on parents.¹³⁴⁶ In describing a “divorced mother” with a severely disabled child who lived alone and who stated she was lonely and had no life outside of care, she is labeled as having diminished resilience.¹³⁴⁷ Mothers like her are criticized as having “allowed” disability to “take over” their lives.¹³⁴⁸

The facts in the legal decisions I examine told a different story. They show highly competent (coping and resilient) mothers objectively struggling with the balance between state versus mother’s care provisioning, and fathers’ versus mothers’ contributions to care, *across parameters*. Rather than there being *too much stress on stress*, as Sobsey alleges, my review showed there is *too little focus on gender*, and in particular on the damaging impacts of the many gendered faces of disability care. Its absence has caused several scholars, such as Hillary Stace, to name disability care as “women’s work”. As such it is devalued. This devaluing was also reflected in a number of decisions I examined, and commented on by some judges, who commended mothers in court for the onerous care work they undertook, some describing their efforts as extraordinary.

I also referred to Franco Carnavale in my review. His work revealed grossly over-burdened caregivers, who are utterly exhausted and desperate for supports of all kinds. My thesis emphasizes that it does not make sense to be concerned about the severely disabled child in isolation from their mother. It revealed that where disability care and support breaks down, foster care is one result. This is state care, the very thing Sobsey fears for disabled children, since in his view public care has proven dangerous for them.

The article written by Donna Haslam referenced in my project refers to community living comprising a vision of care and support that never materialized. She describes the ghosts of that vision as haunting her emotionally. Her words echoed in the cases, especially that of caregiving mother Anne Larcade, who sued Ontario (unsuccessfully) for various kinds of psychological harms in the situation of too little state support. This was the basis of her litigation against the government.

Other authors’ works that appear in my project, such as that of Miriam Edelman, Donna Thomson, Mariane Loene, along with the legal claims of Ontario’s Anne Larcade and Nicole Desmarais, both of whom brought lawsuits in respect of needed support, conclude that complex care requires much greater support, and address mothers’ difficult situations. In the absence of adequate state supported ‘community’ living, it is mothers who have stepped into the yawning care gap. They have done so not

¹³⁴⁵ McConnell et al. *supra* note 531 at 89.

¹³⁴⁶ Scorgie and Sobsey, *supra* note 160 at 198

¹³⁴⁷ McConnell et al, “Fabric of Everyday Life”, *supra* note 531 at 84.

¹³⁴⁸ *Ibid* McConnell et al. *supra* note 531 at 189.

because it is ‘natural’ to do so, but because political approaches that situate responsibility for care and support with them made it necessary. In dismantling care and other supports, governments left caregiving mothers to fend for themselves. My thesis has shown this to be hugely problematic and unjust for both mothers and children.

The literature review (and legal cases) I examined, demonstrate that men are not the heavy lifters in disability care of any kind. Instead, they have had what I earlier referred to as ‘care-privilege’, or what critical theorist Nancy Fraser, whose work I reference, calls an economic “free ride.” As my project has been filtered through my own standpoint as a caregiving mother who was under-supported, it is galling that those who have had care-privilege should be dismissing our experience of inadequate support as personal failure.

Colin Barnes’ observation noted above, was that disabled children fall outside the law. My position is that so do their mothers, and this has been addressed by British legal scholar Jonathan Herring (referred to above). Herring is an expert in care law, and he scrutinizes the unjust responsibilization of mothers in law.

In his analyses, Herring raises the issue of autonomy and how it relates to law, referring to autonomy in its classic liberal articulation. He states that the autonomous man is conceived as self-realizing, self-sufficient, independent and self-reliant, and acts to further his own individual interests. Herring explains that this form of autonomy relates directly to personal choice and the ability to shape one’s life. In this sense, the businessman with rights of autonomy is fully recognized in law. However, he also points out, exhausted mothers with disabled children (such as Green and McKeever described) have little autonomy and are not recognized in law.

Herring also states that caregiving mothers are a legal anomaly. His insight, that caregiving mothers are anomalous in law, impacted how I read the cases. It helped me to see where fact patterns failed to ‘fit’ support law, and failed to fit available claims or the ability of mothers to defend against the claims of others who seek not to pay support. His insight therefore was not merely theoretical. Their anomalous situation has profound implications when it comes to the ability of mothers with severely disabled children to realize rights to support *as a dyad*. By dyad I refer to them as a connected support rights unit. Herring’s insight also in part explains their inability to realize rights as a dyad. As I later show, their circumstances are either not accounted for, or not adequately accounted for, in support law.

Herring’s work also prompted me to think carefully about the issue of autonomy in the cases and legislation I examined when considering the problems caregiving mothers have in accessing support through law. My examination of legal cases, reports and literature about mothers reveal that caregiving mothers are expected to be self-reliant, sooner or later. In this sense, my legal research supports what Herring has observed in Britain, that (eventual) realization of liberal autonomy is expected of caregiving

mothers. In some cases examined, the expectation of maternal financial self-reliance in the setting of heavy caregiving was aggressively pursued in court. My examinations reveal that the classic liberal form of autonomy that is exercised in law, allows for ruthless individualism to be unleashed in the setting of mothers with severely disabled children seeking supports so that they need not continue to live in poverty.

In my thesis, I note that Herring observes that one of the core rights in the liberal world is autonomy and that liberal autonomy relates directly to choice and to the ability to shape one's path in life.¹³⁴⁹ In contradistinction, I provided the example of Mrs. E. who was opposed by disability rights advocates in her plea to be autonomous, and the Supreme Court of Canada in the context of its judgment, seemed to agree that she had no such right.¹³⁵⁰

Returning to critical theorist Nancy Fraser, not only was her work influential in my literature review but her theory accords with what Herring describes in care law. My legal research showed that caregiving mothers are trapped inside what Fraser terms structures of dependency within the capitalist welfare state. The descriptions of Herring and Fraser together helped me to explain what is taking place in many of the legal cases I reviewed, and later discussed, whereby the reality of caregiving mothers' lives and their needs and claims do not "fit" supports as they do for others.

In keeping with what Fraser describes, Kiran Manhas' article notes the continued "ideological distinction" of the public and private spheres in the setting of mothers with children with complex care needs is one that exploits mothers, and that fails to receive legal recognition. In examining a Nova Scotia case, Manhas concluded that the government's calculations of entitlements represent a "gendered devaluation of care." The legal cases I reviewed added to those few she examined, significantly expanding the collection of cases about support of mothers with severely disabled children, and with similar findings, as well as many additional ones.

In an article about their medical research Manhas, along with her colleague Ian Mitchell, describe the requirements of extraordinariness of caregiving mothers, which as noted above, courts refer to when adjudicating caregiving mothers' claims for support. I next comment briefly on the influence of British legal scholar Jo Bridgeman. She argues in her work on mothers with severely disabled children that the view that care is private and that care is a private responsibility *has become entrenched*. That is a reality that Canadian caregiving mothers also confront when they battle for state care. Although some fathers argue in support cases that care is the state's responsibility because Canada is a capitalist-welfare state, in practice it is only weakly a state responsibility today. Bridgeman argues that the state aims to retain care in the private domain, and will battle to do so. This, as she points out and as my research shows, includes the care of children with *extraordinary* care needs. She argues this approach expresses the notion that

¹³⁴⁹ Herring *supra* note 99 at 72.

¹³⁵⁰ Eve *supra* note 511.

public responsibilities towards care are a burden on the state and on society. Bridgeman also points out that women more or less carry responsibility for care alone. I identified this too in cases I examined, and thus her legal research assisted me in my own.

An inability on the part of mothers to provide expected levels of care, or the inability to demonstrate required “extraordinariness” of responsibility as described by Manhas and Mitchell, and Bridgeman, can carry harsh legal consequences for mothers. My thesis addressed the harsh legal consequence of child loss to child protection authorities, in particular the characterization of their circumstance as one of abandonment. This was in reality the result of some mothers’ inability to continue on as extreme caregivers. In keeping with this, my thesis adds to their observations that mothers are heavily burdened, sometimes to the point of giving up on what becomes apparent to them is an impossible mission. This is not state support but rather the fracturing of family relationships.

Throughout my thesis, I have pointed out the relational nature of support needs of mothers with severely disabled children, and the problems these relational needs pose to those seeking support in a legal system that fails to recognize such claims. In that regard, I reviewed the work of relational rights scholars, and, in particular, I refer to Jennifer Nedelsky, who, like Herring, is a care law scholar.

Nedelsky considers rights to be institutional means for implementing core values. She names a few of these values, such as autonomy, security, liberty and equality. She also points out that rights structure trust, responsibilities, power, and care. In her work, she asks how the way in which existing rights have been structured helps address the problem; i.e., what are the patterns and structures of relations that have shaped law, rights and the state? These questions were relevant to my thesis.

In discussing rights, Nedelsky also refers to the presence of myths in theorizing legal structures premised on liberalism. She tackles the issue of autonomy in her research and theory, noting it is conceived in law as a feature attributed to the self as bounded, and lived out by those who are bounded in the way law anticipates. In the myth of the bounded legal self, rights delineate and protect the legal self, and the boundaries of the state. This articulation of rights is seen to create and to support a notion of autonomy that Nedelsky asserts is not attainable for many.

Nedelsky proposes a different version of autonomy, which is relational. She theorizes that autonomy is a capacity that is developed in relationships, and argues that the state has a responsibility for supporting these, essentially because the law constitutes relations in society. However, the state has not lived up to its responsibility, according to Nedelsky. In my research, I identified strong statements from judges about the legal plight of caregiving mothers *vis-à-vis* the state and also about the legal positions of some fathers who actively sought to be legally let off the support hook. Justices Strong, Curtis and others have commented on this, while also acknowledging judges’ ability to access proved legal remedies to poverty and overwork were restricted. Justices Molloy and Linden went out of their way in dissenting

judgments to point out that the relationships of mothers with disabled children trouble law, and that such relationships ought to be supported.

My legal research findings overall accord with Nedelsky's assertion, which is that a caregiving mother's 'self,' is conceived as bounded in law. Her metaphor of the bounded self refers to the solitary and separate self that is envisioned in law. This version of the self runs into difficulty in precisely those areas where caregiving mothers' support needs are being adjudicated. As seen in the statutes and cases I refer to, the state and other parties in support disputes rely on laws that treat caregiving mothers as though their interests are bounded, or as though the support sought is for a single individual who is separate from other individuals in law. This is in spite of the presence of a high needs, unusually vulnerable child in need of extraordinary care, which provides evidence contrary to the bounded individual that the law presumes.

Individual forms of support, like child support, are proven in my project to be a poor fit for mothers with severely disabled children. My project can thus be used to enhance an understanding of reasons why relational envisioning of support rights makes more sense. Nedelsky's work also helped me to examine rights in the ways I describe.

Turning to other academic work in my literature review and employed in my thesis, it highlighted scholars whose work provides analyses of critical consciousness, with two of those considering this concept in the context of caregiving mothers (Melanie Panitch and Elena Mustakova-Possardt). Although I draw from the work of Paolo Freire, renowned for his work in this area, it is primarily the concepts of social psychologist and critical consciousness theorist Maritza Montero, which I rely on in discussing legal cases and their implications.

In *Methods for Liberation: Critical Consciousness in Action* Montero posits general principles for critical consciousness. These include the presence of actions, reflections and dialogue. She describes the praxis-based approach (action-reflection-action) as a practice within which social conditions of oppressed persons may be changed.

The reflection piece problematizes what has been presented to the individual. There is in this activity a conscious construction and reconstruction of the world. Montero asserts that problematization leads to a process of de-naturalizing, that is to say, it entails breaking deeply entrenched beliefs, ideas, and thinking about societal circumstances as being natural the way they are. She posits this is useful in settings where people's lives are difficult, painful, hard and unfair.

The result of these practices is a mobilization of consciousness from the uncritically accepted vision of reality to a different one, where life is transformed. In this process, new knowledge is generated and there is heightened awareness of social relations that cause people to question the hegemony of certain ideas. Montero states that problematization may begin with a doubt or a question, and can foster

the development of political understanding. And she describes a ‘trigger’ effect as starting the critical process of analysis. My thesis uses these ideas.

For example, Montero explains that individuals become adept at “learning” from external constructions of their experiences, stating that one response to the force of restructured consciousness is a willingness to engage in conflict and to make use of available resources to change society. It is the force of this *restructured* consciousness which enables individuals to set out their demands.

In my thesis, problematization is seen as a process leading caregiving mothers to acquire the ability to claim rights, contest law, and a willingness to dispute how law is applied to them. Justice O’Connell in an endorsement of a child protection matter chose to include the information that “[t]he respondent mother does not agree that she has abandoned M.A., but rather that she was no longer able to care for him.”¹³⁵¹ This reflects a mother’s counter-framing of her legal circumstances, which in this case fell outside the ideology of the “failed mother” in child welfare.

I suggested in my project that what the present institution of patriarchal and ableist motherhood presents to caregiving mothers with severely disabled children is everything mothers with non-disabled children must deal with (intensive selfless mothering, being responsabilized for children, being blamed and judged when things do not go according to society’s plan for a child). Then in addition to that, there is the devaluation of the severely disabled child, the continued normative expectations, the blaming of caregiving mothers for not being more like mothers who have non-disabled children and the higher financial costs to be incurred by caregiving mothers.

A mother who is not *critically* conscious may realize she needs some support and may ask around and learn about her right to claim child support. When she becomes aware of her entitlement to bring a claim, and how to go about doing so, she will have a new rights consciousness that she previously lacked. However, if she has a severely disabled child and attends court and finds her application is met with vehement and unyielding opposition and allegations that do not match her reality, she may begin the process of praxis (or she may give in and go home). If she engages in problematization, as I suggested in my project many caregiving mothers do, then she may become one of the caregiving mothers who recognize they need to educate themselves about the law, and the assumptions undergirding it, to allow her pursue a particular claim or bring an appeal and perhaps do more than that.

In critical consciousness the goal shifts so that it also entails changing legal practice or changing the law or policy because now she wants more than just child support, she also wants a particular form of justice, which includes recognition of the legal plight of mothers and their severely disabled children. My thesis described mothers who sought to change the *status quo*. My analyses, as described, built on the ideas of Panitch as well as Mustakova-Possardt. For example, Panitch described Audrey Cole as a

¹³⁵¹ *J.A.1 and J.A.2 supra* note 1019.

critically conscious activist mother.¹³⁵² Panitch noted in a 2006 document that Cole (and others) had moved beyond personal grievances in her advocacy, to become politicized in her ideas about motherhood.¹³⁵³ Ten years later, Cole's middle-aged son's lawsuit, directly facilitated by his mother as his litigation guardian and analyzed in my thesis, frames Cole as a critically conscious *litigating* mother.¹³⁵⁴ The decision in *Cole* 'shapes consciousness'¹³⁵⁵ concerning health care rights of severely disabled people and in so doing helps others to consider similar litigation to advance a shared goal.¹³⁵⁶

My work adds to theirs, showing mothers making *legal* demands on the state, and who do not in their claims to support accept the "compartmentalization of public and private", as described by Mustakova-Possardt in discussing her interview with a caregiving mother.¹³⁵⁷

Having further regard to their legal demands, I next point to conclusions that can be drawn from their litigation.

Conclusions Drawn From The Legal Research

In this section I provide conclusions from my legal research. As seen, the thesis is comprised of eight chapters. In Chapter Two I provided my research pathway and included an explanation of my conceptual frameworks, which drew from feminist standpoint and critical consciousness theory. In Chapter Three I provided an interdisciplinary review of the literature in areas addressing aspects related to support to mothers with disabled children.

Moving ahead to Chapter Five, in it I sketch the support law and policy landscape as it pertains to mothers with disabled children. This chapter painted a picture of support offered by government as being in silos, with multiple ports of entry to support offerings. Thus the state has structured support such that mothers cannot get support they need in one place. They must apply for it in many different places, in different Ministries, with different definitions of disability and different eligibility requirements. This carries with it numerous problems and barriers and adds an administrative and time burden to those other burdens mothers already shoulder.

An additional problem noted in Chapter Five is that cases, legislation and policy rest on shifting sands. If they are changed or removed, government cannot be held accountable to mothers. This adds a

¹³⁵² Melanie Panitch 2006 *supra* note 150 at 158, 159, and in other sections of the text as well.

¹³⁵³ Melanie Panitch 2006 *ibid* note 150 at 9.

¹³⁵⁴ This is my own interpretation of the lawsuit in which Ian Cole was named at plaintiff at the Ontario Human Rights Tribunal in a case his mother was instrumental in bringing. See *Cole v Ontario (Health and Long Term Care)*, 2016 HRTO 497.

¹³⁵⁵ The term 'consciousness-shaping' is used in Panitch at 27 attributed to Karin Sacks (1988) *Gender and Grassroots Leadership*. Eds A. Bookman and S. Morgen. Women and the Politics of Empowerment. (Philadelphia: Temple Press 1988).

¹³⁵⁶ *ibid*

¹³⁵⁷ Mustakova-Possardt 2003 *supra* note 145, at 126.

layer of complexity and stress for mothers in an already complex ‘system.’ Policy is also balkanized; I provide the example of respite, which in Ontario is accessed through different Ministries and for which there have been extensive wait lists.

In Chapter Four I examined features of disability care. Importantly the ideology of care that surrounds mothers with severely disabled children was discussed as oppressive. In this chapter I introduced four models of disability: social model; medical model; charity model and what I name the combined approach— a relational and non-adversarial model of care.

My analysis revealed that caregiving mothers resist the characterizations in different models of disability that have been applied to them and their children, and which have been oppressive, each in their own way. The charity model masks mothers’ burdens of care, the social model pathologizes mothers’ care burdens, while the medical model holds that it is the disabled child who is a burden on the family and on the state. I went on to describe a re-theorization of mothers’ burdens of care, and reformulate that into a new combined model. The work of caregiving mother and scholar Sarah Green was instrumental to this endeavor. The combined model deals openly with maternal burdens of care and does so in a manner that allows their alleviation to be considered. I posited a number of as yet unidentified (by the state or social model proponents) burdens of care on mothers. One, for example, is the need to engage in and pay for legal battles while caregiving. Burdens of care as I noted, vary in nature, degree and impact. For example, some of the research described ‘catastrophic’ burdens of care, while others referred to requirements of ‘extraordinary’ care.

In Chapter Four I applied insights from these models of disability to my critique of the above mentioned celebrated 1981 disability rights case (*Eve*) that was heard at the Supreme Court of Canada. I examined various stages of this litigation, which was brought by a caregiving mother. This case underscored that caregiving has been socially assigned as a lifelong obligation, without that reality having been *overtly* acknowledged, including in law. As such, I commented on the coercive elements of law when it comes to mothers and disability care.

Chapter Four concluded that assumed care by mothers, no matter their personal circumstances, is oppressive. And I argued that it is through a process of critical consciousness, such as one may presume Mrs. E acquired when society and the Court would not allow what she requested, that permits mothers to escape the shared societal vision imposed (even if they must continue to provide most or all of the care).

The models of disability examined in this chapter, along with my analysis of Mrs. E’s situation, informed my examination of legal cases in subsequent chapters, to which I now turn.

Chapter Six dealt with disputes with the state. Although those cases that come to court do not represent all circumstances, in cases I examine, both private parties and government battled not to have to

support mothers with severely disabled children. In some cases government and fathers asserted that the other should have responsibility for such support.

The cases suggest it is important to government to set precedents with caregiving mothers. A strong state stand is taken against the interests of mother and disabled child where *public* support is at issue. This has been witnessed in respite, disability pension eligibility and other public law cases brought by caregiving mothers. In one case, with a child disability tax credit at issue, the government put a disabled child on the stand to question him about the level of care he received from his mother. This practice contradicts the ideology of the noble caregiving mothering that is described in Chapter Four, and it exploits the notion of the self-sacrificing special needs mother. It is also not in the best interests of the child to be treated in this manner. My research showed that caregiving mothers often could not ‘win,’ i.e., they were unable to obtain adequate support.

Part of the legal analysis resulted in findings concerning the place of liberal notions of autonomy upon which support law for mothers with severely disabled children is premised, and contrasting that with relational autonomy. Caregiving mothers simply cannot inhabit the bounded form of autonomy liberal law presumes. In relation to Nedelsky’s ideas, the example in Chapter Six is provided by caregiving mother, Tali Lalkin. She was ‘autonomous’ in the classical liberal sense (i.e., she was single and self-supporting with a six figure income). Her ‘autonomy’ did not remedy the issue she encountered in relation to a state support benefit she applied for. Her income level was held to be too high and thus she was denied her support. The problem was half her income went on disability costs for her disabled children. In alignment with Nedelsky’s theory, the law constitutes Lalkin as the custodial mother and assigns her the relational complex care of her children, but then rather than supporting this assigned relational care, the government strives not to support it or her in the amount needed.

On the other hand, where caregiving mothers have been legally accorded discretionary state support *in relationship* with their disabled children, one sees government rejecting shared support, in favour of child loss and disabled child wardship. This rejection includes a legislative return to individualistic forms of support when shared forms of support are repealed.

Other cases concerning government benefits cases revealed that the ‘back of the envelope’ calculations of needed support to be made discretionarily available ignore what government’s own research and the research of others has shown, which is that care of severely disabled children is expensive, effortful, and energy and time consuming. Such categories of support likewise treat the disabled child as a unit of support unto him or herself, even though this is completely divorced from the realities of his or her care.

The public law cases also revealed that when there are problems with support (inadequacy, errors, material changes and so on) this can result in time-consuming complications and disputes. There may be

battles for caregiving mothers to show their and their child's eligibility, and to show their continued eligibility. There are battles to show that more support is needed than was awarded. The issue of material change in circumstance is a critical area in support litigation, both in public law and private law support. While it is necessary to permit changes in means to be demonstrated, challenges to needs are often vexatious and introduce precarity into mothers' lives and budgets.

As seen in some of the other benefit cases, caregiving mothers cannot enjoy any economic certainty from one year to the next. Continued eligibility must be shown. Even where support has been awarded in the past, cases reveal the very same roadblocks may appear year after year, even after the same issue has already been litigated.

The public law cases reveal a lack of acknowledgment of the problems with quanta of support and the weak delivery of critical health services. Although the examples reveal caregiving mothers badly need nursing care relief, supports are structured so that there is no government accountability when nurses fail to show up for a shift. There is some discourse around the emotional costs of all this to mothers, but no legal discourse.

Cases revealed mothers' desperation in the area of respite. Yet, respite care funding, although absolutely *essential*, appeared in cases (both public and private) to be a point of contestation. Cases I discussed show that even those mothers with high social capital, high education and large incomes cannot do what the state expects them to do. This includes caregiving mothers who are lawyers who understand the court system, and a physician who was accustomed to providing health care.

Together the cases I examined reveal barriers to accessing adequate support. I provided an example of a case that straddled public (child welfare) and private (family) support law. Both the state and the father left court without having to offset the mother's costs of care. Such barriers are built into the legislation, which, as Nancy Fraser describes 'contains' their so-called 'domestic' claims.

As demonstrated in the facts of case after case, across provinces and territories, the need for support of mothers with severely disabled children is a *shared* need. Conceiving of support as individual has resulted in complex disputes where courts at times have struggled to find just solutions. This complexity is further reflected in private support law.

Moving on to discussion of the conclusions from my legal analyses in Chapter Seven, which examined private lawsuits (i.e. disputes between private parties), I also described private law as being much less private than one might assume, since government can and does become involved. It does so for example, if private decisions threaten to cement government support obligations (*King*¹³⁵⁸). Government has also amended a private support statute in another case as well (*Krangle*¹³⁵⁹).

¹³⁵⁸ *King supra* note 1086.

¹³⁵⁹ *Krangle supra* note 765.

Another finding is that government can be seen to be in favour of disability rights to support when it is to be realized (theoretically anyway) through *private* support law. Thus government may not as vociferously oppose a caregiving mother's claim, or it may not even take a position (*Coates*¹³⁶⁰). Note that a private party claim to change family law support to allow for support claims to be brought against other private parties (*Vivian*¹³⁶¹, *Coates*¹³⁶², *M v H*¹³⁶³) results in less financial 'burden' on the state. For example, the maternal 'win' in the *Coates* case, was that the court held the *FLA* was discriminatory in its barring unmarried women from claiming child support for their age of majority disabled children unless they were in school full time. Although this ruling is an improvement over what was in place, more avenues to private law support such as the ability to claim child support is not what is most required. State support is. Simply put, family law, as the legal cases reveal in chapter six, is inadequate to the task of ensuring needed levels of support or security of support. Moreover it usually involves a fight on an uneven playing field.

My project critiqued government data collection in the area of child support arrears. I argued that the data that is collected misrepresents both typical mothers and *caregiving* mother's realities, in ways I discussed. Even though all children are entitled to child support in the support framework, it is tailored for non-disabled children, and fails to address support needs of severely disabled children, whose mothers are already out of pocket. What is seen is that the needs of the severely disabled child must be fought for as extraordinary expenses under s 7 of the FCSG. This is the only legal avenue available to caregiving mothers to claim what are for them the *usual* costs of care.

In addition the family law cases highlight that *care* support is not synonymous with *child* support. But family law cannot distinguish. This is similar to the unjust conflation of wardship with care (Chapter 6). The support provisions as presently enacted are blunt instruments not up to the task of helping caregiving mothers to realize their legal rights to support.

Another important issue made apparent in cases examined is that ableism manifests in some family law practice. For example, it is seen in cases where one parent minimizes or denies the severe disabilities in submissions crafted by their legal counsel. This undermines mothers' claims.

As cases showed, although there is a support provision for all minor children in family law, it does not always translate into money in the bank, for the reasons I discussed. Moreover there is no 'freestanding' complex care support claim in family law provisions. And even if there were, it would predictably be highly contested, likely in a manner seen in *Vivian*.¹³⁶⁴

¹³⁶⁰ *Coates supra* note 871.

¹³⁶¹ *Vivian supra* note 997.

¹³⁶² *Coates supra* note 871.

¹³⁶³ *M.v H*. [1999] 2 SCR 3, 43 OR (3d) 354.

¹³⁶⁴ *Vivian supra* note 997.

Once a severely disabled child turns 18, caregiving mothers must provide proof of why they need continued child support, *as if the disabled child's support circumstances have suddenly changed*. For a severely disabled child, need of support remains high. Age is often not a change of the 'child's' *care* circumstances (recalling that material change of circumstances is a legal basis for review of support). All caregiving mothers are aware of this, but the law does not account for it. Even though there are provisions in family law permitting mothers to bring claims for support for age of majority disabled children, for many mothers they are not a realistic option. Such provisions require mothers to advance claims. That alone has a deterrent effect of letting some fathers off the support hook.

Spousal support provisions are another avenue of support. Yet, in the family law context, there is no category within spousal support for the *caregiving* mother, i.e with a child with severe disabilities. Thus normative spousal expectations can be placed on caregiving mothers. Moreover, claims for spousal support may be bitterly opposed. They require a payor with means to pay, but as cases reveal, it does not mean they will. Spousal support is also an uncertain remedy, with contempt of court, material change in circumstances of the payor, and a payor's death being reasons for this uncertainty. The cases do not lead to the conclusion that spousal support is a feature caregiving mothers should be expected to rely upon. To act as though it is an acceptable route to support, is to have mothers assume all of the risks associated with this form of support, in addition to the risks associated with the caregiving itself. The fact is most men cannot afford to pay or will fight not to have to.

There are other conclusions that can be drawn from a comprehensive consideration of the public and private law cases together. For example, cases show that caregiving mothers perform the lion's share of care, and that it is primarily mothers who pay the financial, social and health costs for so doing. Cases also reveal that although some courts laud mothers for this, in other cases mothers are attacked in the submissions made by parties, and at times their circumstances are not factored into decisions, in spite of the fact that the care work they do is without remuneration. This suggests in some cases the impacts of heavy care performance have not been understood by courts.

However even where mothers are lauded by courts for essential care performance, there is *still* status misrecognition. My research revealed that this is compounded by the additional features of the exclusion of mothers with severely disabled children from a variety of other needed forms of support, not provided for in law (i.e. caregiving mother's pensions, relief when they themselves become ill, financial support after a severely disabled child dies and others).

The plight of caregiving mothers vis-à-vis support was addressed in a variety of cases. Notably, the late Federal Court Judge Alan Linden recognized the sacrifices that caregiving mothers make in providing care for which they are not rewarded by society or served by law; in one case he referred to

law's unjust normative expectations. He also brought attention to the relational nature of mothers' care for their severely disabled children and the challenges in related legal doctrine.¹³⁶⁵

As in public law, cases I examined in private law reveal that the circumstances of mothers with severely disabled children do not fit within existing legal frameworks. This resulted in no suitable remedy, although some judges seemed eager to creatively find one.

The existence of two support domains (public and private) itself fomented disputes in family law, while also setting the stage for harsh government policy that included clawbacks in the money needed by less well-off caregiving mothers. Some mothers found themselves having to defend against government to retain the private disability support payments made willingly by fathers. They fight for private support, and then must fend off government. In private support disputes some payors argue mothers are freeloaders and should seek payment from the state instead. It may be the case some judges believe that is a viable option, where it is not.¹³⁶⁶ Legal cases further showed that family law support claims shared space with child welfare claims. Together these cases reveal that caregiving mothers have significant responsibilities without the needed legal rights to support.

There are a number of legal tools available to mothers denied their rights. Below I examine these, and their potential to redress the situation of mothers and their children with severe disabilities.

Legal Remedies for Mothers with Severely Disabled Children

Existing legal remedies, which have been examined throughout my thesis, were seen to present, overall, substantial barriers. Moreover an individual "win" on a case-by-case fact-specific basis often only helped the litigant, and not others. In light of this, something else is needed to remedy the problems caregiving mothers face accessing supports. Different types of legal remedies can be employed to address the situation described in the preceding chapters. In this next section I discuss five areas of law that caregiving mothers might consider as strategies for realizing legal changes. In this order, I address administrative law, tort law, human rights codes, international law and constitutional law. I end this section by focusing on the most promising avenue amongst these, and that is a possible claim under s12 of the *Charter of Rights and Freedoms*.

Administrative Law

Administrative law is public law that defines and adjudicates issues concerning the legal limits on discretionary decision-making by government under a statute. Thus, for example, administrative law remedies would include a government decision not approving an application for child disability support

¹³⁶⁵ *Harris supra* note 1399.

¹³⁶⁶ *King supra* note 1087

made available under a given statutory provision to which caregiving mothers may apply for a discretionary benefit.

When government makes a discretionary decision that a caregiving mother believes fails to award her sufficient funds, or services, she usually can have recourse to seek judicial review of the decision by a court with jurisdiction to do so.¹³⁶⁷ Ordinarily, courts can undertake a substantive or a procedural review of government action. They will examine the government decision to discern if it was *ultra vires* or outside its powers, or constituted improper fettering of discretion, or whether another abuse of discretion had occurred.

There are a number of remedies in response to government misuse of its discretion that may be provided, upon review. For example a court can quash a government decision, or send it back for reconsideration as seen in *Nieberg*,¹³⁶⁸ an example discussed earlier in my thesis, where a government decision was quashed on review and sent back to have the quanta of support re-determined.

Administrative law plays a significant role in access to supports by mothers with severely disabled children, simply because so many of the supports they require are provided discretionarily by government pursuant to statutes and regulations. As seen in my project, there is the potential through administrative law channels for some mothers to realize entitlement to or higher awards of support through judicial review. However, legal scholars such as Lorne Sossin have pointed out that government has broad discretion in its administrative decision-making. That is an issue because it permits bureaucrats wide latitude in their decision-making, and the present culture of government bureaucracy in the area of support is not a generous one. This situation fosters a harsh and litigious environment surrounding support benefits that mothers with severely disabled children require.

Even if successful, judicial review is expensive, unpredictable, permits no damage awards, and cannot change the entire support system, so it is often only helpful on a case-by-case basis. Administrative law is complex and replete with technical requirements. Such a challenge requires professional assistance and specialized expertise. However, a determination that government decision-making was *ultra vires* its power would affect others too, and in that regard this area of the law offers at least some potential to remedy some difficulties caregiving mothers encounter in accessing supports. The chief reason administrative law is unsatisfactory however is that it is a complex area of law, with built-in limitations in terms of what can be achieved.

¹³⁶⁷ I say ‘usually’ since it was unclear respecting s 30 of the *CFSA* (Special Needs Agreements) that there was recourse to review of decisions refusing to enter into an agreement with a mother or ending an agreement against the mothers wishes. *CFSA* 1991 (This section of the *CFSA* was removed in 2017 after this research was conducted).

¹³⁶⁸ *Nieberg supra* note 785.

Tort Law

People can sue for certain types of civil wrongs or harms that resulted in damage to them. Private parties may be sued in tort, as can government. There are several different kinds of torts; those most likely applicable to the situations of mothers with severely disabled children are negligence and misfeasance in public office. Where a claimant is successful, monetary damages may be awarded.

Tort law could potentially redress civil harms to mothers and their severely disabled children in the setting of extremely low levels of government support. For example, a class action negligence claim was recently commenced concerning years-long government wait lists in the developmental disability sector in Ontario. A benefit to doing this, as some judges (Justice Linden for example) point out, is engaging the ombuds role of tort law to act as a watch-dog over government activities.¹³⁶⁹ However, where caregiving mothers are concerned, in order to sue in negligence, they must convince a court that there was a private law duty of care owed by government to them as a first step, and case law establishes that it is very difficult to attack the government for its policy.¹³⁷⁰

Tort law has many drawbacks for caregiving mothers, including the high cost of litigation, and the length and uncertainty involved. However, it is chiefly the sheer complexity of a dispute in this area of law that presents as the main drawback to its use by caregiving mothers.

Human Rights Codes

Human Rights Codes are provincial and federal legislation applicable to public and private activity that aims to protect equal rights in areas such as services, housing and employment. There are a range of prohibited grounds of discrimination under the Ontario Human Rights Code (OHRC), including sex, disability and family status. The family status category is intended to protect a caregiving family member from discrimination. It is a relational provision in a sense, since it protects the caregiver, and derivatively the cared for. Unfortunately protection under the OHRC has proven insufficient where mothers with *severely* disabled children are concerned, as seen in the case of Cindy Moore, described earlier in the thesis.¹³⁷¹

Not only human rights claims have proven problematic for caregiving mothers. The policy manual of the OHRC itself, which defines family status as a parent-child relationship, is also problematic.¹³⁷² For instance, it discusses the relationship between family status and the ground of

¹³⁶⁹ A. M. Linden, "Tort Law as Ombudsman." (1973) 51:1 Can Bar Rev 155-168.

¹³⁷⁰ *R v. Imperial Tobacco Canada Ltd.*, 2011 SCC 42, 3 SCR 45

¹³⁷¹ *Moore supra* note 1040 at 9.

¹³⁷² Ontario Human Rights Commission. Policy and Guidelines on Discrimination Because of Family Status, Toronto: OHRC, 2007). *supra* note 1039.

disability discrimination, using the example of the requirement of an employer to accommodate a mother employee with an autistic child, as comprising a legal obligation. Unfortunately, in this example the family status provisions in the human rights legislation are *under-inclusive* of the needs of working mothers with *severely* disabled children, because their circumstances are vastly more complex and much more unpredictable than the example provided. This means this avenue of redress is subject to non-contextual approaches: i.e. working as the mother of a disabled child is a very different context than doing so with a *severely* disabled child. The accommodations required of an employer are of a different order. This provides another example of the anomalous-to-law caregiving mother that Herring described. It also is an example of the difficulty with the model of the bounded self being applied to a caregiving mother employee, who has life and death care obligations that crop up without warning. Legal scholar Judith Mosoff, whose work is referenced in the thesis, observed that those individuals who are furthest from the norm are helped the least by human rights codes. Her research found that individuals with severe disabilities appeared rarely in decisions.¹³⁷³ The chief reason that Human Rights Codes are not the most promising avenue is that provisions are under-inclusive of the realities of maternally complex care in the setting of *severe* disability.

International Human Rights Law

As previously stated, Canada is signatory to a several international human rights instruments. Most relevant to my thesis, are the United Nations Convention on the Rights of the Child¹³⁷⁴; the United Nations Convention on the Rights of Persons with Disabilities (CRPD)¹³⁷⁵; the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)¹³⁷⁶; the International Covenant on Economic, Social and Cultural Rights (ICESCR)¹³⁷⁷ and the Universal Declaration of Human Rights (UDHR).¹³⁷⁸ These instruments set out a range of human rights obligations to which Canada is committed.¹³⁷⁹ They have bearing on Canadian (domestic) law.

The Supreme Court of Canada moreover “has repeatedly recognized that when interpreting the scope and content of human rights, Canada’s international obligations and relevant principles of

¹³⁷³ Judith Mosoff. “Is the Human Rights Paradigm Able to Include Disability” *Who’s In-Who Wins What-Why* (2000). Queen’s LJ, 225.

¹³⁷⁴ *CRC*, *supra* note 880.

¹³⁷⁵ *CRPD*, *supra* note 35.

¹³⁷⁶ *CEDAW*, *supra* note 893.

¹³⁷⁷ *International Covenant on Economic Social and Cultural Rights*, 16 December 1966, 993 UNTS 3 [ICESCR].

¹³⁷⁸ *Universal Declaration of Human Rights*, GA Res 217(III), UNGAOR, 3d Sess, Supp No 13, UN Doc A/810, (1948) [UDHR].

¹³⁷⁹ Canada has ratified all of these instruments. Department of Justice Canada, “International Human Rights Treaties to which Canada is a Party” online: <<http://www.justice.gc.ca/eng/abt-apd/icg-gci/ihrl-didp/tcp.html>>.

international law set out the minimum level of protection” to which people are entitled.¹³⁸⁰ The Supreme Court of Canada decision in *Divito* supports this assertion.¹³⁸¹ Referencing *Divito* and regarding the role of these instruments in the legal rights to support I examined in my thesis, Gilmour states that “the understanding of domestic law is reinforced by international human rights agreements to which Canada is a party.”¹³⁸²

All of these instruments have significance to my project and this can be readily discerned in the literature and legal cases I examined in my thesis (*Coates* for example).¹³⁸³ I point out but a few further examples here. The introduction to CEDAW states that the provisions for maternity and child-care are proclaimed as essential rights and incorporated into all areas of that Convention whether dealing with employment, family law, health care or education. Yet domestic support law and how it is dealt with by government do not reflect CEDAW’s aims. Article 25(2) of the UNDHR, provides that motherhood and childhood are entitled to special care and assistance.¹³⁸⁴ State responsibilities to mothers are plain and this does not exclude mothers with severely disabled children.

The CRPD and the CRC both contain provisions for disabled children. Article 20 of the *CRC* provides that, “[a] child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.”¹³⁸⁵ This has application to situations where caregiving mothers require state supports. The CRPD, ratified in 2010, provides that states have binding obligations concerning the realization by disabled children of their rights. Article 23.5 provides if immediate family cannot care for a disabled child, states parties shall, “undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.”¹³⁸⁶ Again, this has relevance to the support rights of mothers with severely disabled children, particularly in situations such as that described by the Ontario Ombudsman in 2005, described earlier. In addition, the Best Interests of the Child Principle expressed in international law must inform government decisions pertaining to children, including those who are severely disabled. Yet, as seen in many in legal cases involving state support for severely disabled children, it has not.

In spite of these provisions, the situation of mothers with severely disabled children is often absent from deliberations at all levels. For example, The First Report of Canada to the Committee on the

¹³⁸⁰ Joan Gilmour. Legal Capacity and Decision-Making at 372 in Canadian Health Law and Policy in Erdman, Gruben and Nelson (eds) 5th Ed. (Toronto, LexisNexis Canada 2017) .

¹³⁸¹ *Divito v Canada (Public Safety and Emergency Preparedness)*, 2013 SCC 47, [2013] 3 SCR 157.

¹³⁸² Gilmour, *supra* note 1387 at 372.

¹³⁸³ *Coates supra* note 871.

¹³⁸⁴ *Universal Declaration of Human Rights*, GA Res 217(III), UNGAOR, 3d Sess, Supp No 13, UN Doc A/810, (1948) [*UDHR*]. Technically this is not a treaty.

¹³⁸⁵ *CRPD supra* note 35 art.20

¹³⁸⁶ *CRPD, supra* note 35, art. 23.5.

Rights of Persons with Disabilities that was filed in 2014,¹³⁸⁷ under the heading ‘Children with Disabilities’, sets out Federal government initiatives for disabled children in 140 words. There was no discussion of the needs of caregiving mothers. In the Concluding observations on the initial report of Canada¹³⁸⁸ the direction given by the UN committee is for Canada to introduce guidelines among all levels of administration on how to implement the principle of the best interests of the child in the design, implementation and monitoring of legislation and policies concerning children with disabilities. The primary reason that International Human Rights Law is of limited use on its own is that it is not directly enforced by Canadian courts.

Constitutional Law

The *Charter of Rights and Freedoms* forms part of Canada’s Constitution, and limits government action. Individuals who believe that a law violates one of their rights listed in the *Charter* may bring a claim to court or an administrative tribunal. In this section I briefly address three rights contained in the *Charter* that are most germane to my dissertation: s15 (right to equality), s7 (right to life, liberty and security of the person), and s12 (right not to be subjected to cruel and unusual treatment). Below I comment on the ability and inability of caregiving mothers to make use of these sections of the *Charter* to assert or win adequate support.

Section 15 of the *Charter* provides that “Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.” Women in a variety of circumstances have relied on s.15 in an effort to advance their equality rights. Cases include *Brooks*¹³⁸⁹ (maternity leave), *Withler*¹³⁹⁰ (widow’s pensions), *Tomasson*¹³⁹¹ (adoptive mothers parental leave) and *Harris*¹³⁹² (disability pension for disabled caregiving mothers), amongst others. Likewise, disabled people and their advocates have relied upon s.15 to advance equality rights claims. Some such cases include *Eldridge*¹³⁹³ (health care) and *Granovsky*¹³⁹⁴ (pension). Interested

¹³⁸⁷ Government of Canada, *Convention on the Rights of Persons with Disabilities, First Report of Canada* (Ottawa: Author, 2014). There has been one subsequent to that referred to below.

¹³⁸⁸ *Concluding observations on the initial report of Canada*, UNCRPD, 17th Sess UN Doc CRPD/C/CAN/CO/1 (2017), at art 18 (d). online<
<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPFPRiCAqhKb7yhshFUYvCoX405cFaiGbrIbL87R7e4hNB%2FgZKnTAU8BqK7FKCyFSQGUzS4dKwSRSD%2FCPUoSzW7oP9OI5lweGr%2Br%2B7wpRzQbCN1rv%2B%2BwMd4F0fZ>>.

¹³⁸⁹ *Brooks v Canada Safeway Ltd.*, [1989] 1 SCR 1219, 59 DLR (4th) 321

¹³⁹⁰ *Withler v Canada (AG)*, 2011 SCC 12, [2011] 1 SCR 396.

¹³⁹¹ *Tomasson v Canada (AG)*, 2007 FCA 265, [2008] 2 FCR 176

¹³⁹² *Harris v Canada (Minister of Human Resources and Skills Development)*, 2009 FCA 22, 4 FCR 330.

¹³⁹³ *Eldridge v British Columbia (AG)*, [1997] 3 SCR 624, 151 DLR (4th) 577

¹³⁹⁴ *Granovsky v Canada (Minister of Employment and Immigration)*, 2000 SCC 28, [2000] 1 SCR 703.

parties, including mothers as named plaintiffs and as *guardians ad litem* for their disabled children, have brought claims to advance the equality rights of disabled children, for instance in the autism litigation.¹³⁹⁵

Notably, the *Charter* is aimed at ensuring constitutional rights for *individuals*. This reality poses problems for litigating caregiving mothers who represent a *relational* situation.¹³⁹⁶ There are cases demonstrating that the *Charter* is challenged to capture the complexity of relationships that require protection from equality rights breaches or other constitutional rights infringements. This is in part because those adjudicating claims often revert to formal tests for equality (i.e. treat likes alike), which do not permit an accounting for the inequality experienced by mothers with severely disabled children. This happens notwithstanding the rejection by the Supreme Court of Canada of this approach to equality. Adjudicators are reluctant to use contextual approaches, which makes it difficult for them to “see” how legal arrangements further inequality. This was apparent in *Harris*, a case examined in the dissertation, involving a disabled mother with a disabled child, who claimed employment benefits.¹³⁹⁷

Section 15 has however been successfully used to advance the support rights of severely disabled adult children living with their lone mothers.¹³⁹⁸ As well, s15 may present an opportunity for caregiving mothers to advance an equality rights claim based on “enumerated and analogous grounds”.¹³⁹⁹

However, one problem that arises in the determination of s 15 claims is that fact patterns are frequently interpreted in the context of ‘formal’ equality, despite jurisprudence to the contrary. What this means is that our courts are opining one way, but then deciding in another. When this occurs, it fails to ‘capture’ inequality in the circumstances of ‘care’, or ‘mothers with severely disabled children who require substantive approaches to equality rights determinations. Arguably, caregiving mothers could claim discrimination based on analogous grounds, but this is complex and the result uncertain. The continued use of formal rather than substantive interpretations of equality present a chief reason why this avenue is not the most promising one.

Mothers and disabled children through their legal guardians have also relied on s 7 of the *Charter*, to advance rights to support. Section 7 provides that “Everyone has the right to life, liberty and

¹³⁹⁵ *Wynberg v Ontario* (2006), 82 OR (3d) 561, 269 DLR (4th) 435 (ONCA); *Auton (Guardian ad litem of) v British Columbia (AG)*, 2004 SCC 78, [2004] 3 SCR 657.

¹³⁹⁶ *Deol v Canada (Minister of Citizenship and Immigration)*, 2002 FCA 271, [2003] 1 FCR 301 involved a woman claiming discrimination as a result of treatment of her parent. The applicant’s father was rejected by immigration authorities on the basis of his medical disability. His daughter claimed disability discrimination against herself. However, the court found she lacked standing to assert her father’s rights, as though they were hers. Justice Evans found that even if the *Charter* were to apply to the father abroad, a person cannot establish denial of their rights to equality by proving discrimination against another.

¹³⁹⁷ *Harris supra* note 1399.

¹³⁹⁸ Under the Ontario *Family Law Act* in *Coates supra* note 871.

¹³⁹⁹ See *Harris supra* note 1399 Justice Evans at the Federal Court Trial division opined “I am prepared to accept for the purpose of this application that “parents of a child with disabilities” constitute an analogous ground for the purpose of section 15.” *Harris, supra* note 1399 at para 92.

security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice”.¹⁴⁰⁰ Section 7 has been relied upon successfully by a mother in child protection litigation. *New Brunswick v G (J.)*¹⁴⁰¹ held that failure to provide legal aid to a mother who needed to reply to a child protection application breached her s.7 right to security of the person. This case underscored that economically vulnerable mothers with children at risk of apprehension do have constitutional rights.

Section 7 was also one of two *Charter* rights relied upon in a challenge to a provincial family law provision in relation to adult child disability support. However, the s 7 challenge was ultimately unsuccessful.¹⁴⁰² Section 7 was relied upon in autism litigation.¹⁴⁰³ These claims too were unsuccessful.

The Supreme Court of Canada decision in *Gosselin* provides another example of narrow judicial interpretation of s 7.¹⁴⁰⁴ *Gosselin* involved a representative plaintiff of a large class in a class action lawsuit, who challenged the constitutionality of Quebec’s *Social Aid Act*. The statute included a provision protecting social rights, and Gosselin asserted claims of s 7 (as well as s 15) infringements. She claimed the *Act* infringed her rights because it provided her with a below subsistence benefit. The majority dismissed the claim as non-justiciable, holding that to succeed, Gosselin would have to show special circumstances that justified imposing a positive obligation on the state to act. In her dissenting judgment, Justice Arbour held that the *Act* did infringe Gosselin’s s7 rights and that the government did have an obligation, under the particular facts, to support Gosselin.

Even the two most promising s7 cases, *G.(J.)*¹⁴⁰⁵ and *Gosselin*¹⁴⁰⁶, therefore have built-in limitations. Neither is on all fours with the situation of mothers with severely disabled children. In short, caregiving mothers would have an uphill battle to show that s7 imposes positive obligations on government to provide economic support under this section of the *Charter*. In conclusion s 7 still does not reliably serve to advance socio-economic rights, since it is still the case that courts are reluctant to find that it imposes positive obligations to support on government.

Lastly I discuss and apply s12 of the *Charter*, which states “Everyone has the right not to be subjected to any cruel and unusual treatment or punishment.”¹⁴⁰⁷ Section 12 has been successfully relied

¹⁴⁰⁰ *Canadian Charter of Rights and Freedoms* *supra* note 10.

¹⁴⁰¹ *New Brunswick (Minister of Health and Community Services) v G.(J.)*, [1999] 3 SCR 46, 216 NBR (2d) 25.

¹⁴⁰² *Coates* *supra* note 871.

¹⁴⁰³ For example, the *Sagharian* case relied in part on s. 7 of the Charter, *supra* note 1070. Such limited success is significant.

¹⁴⁰⁴ *Gosselin* *supra* note 9.

¹⁴⁰⁵ *G.(J.)* *supra* note 1408.

¹⁴⁰⁶ *Gosselin* *supra* note 9.

¹⁴⁰⁷ *The Canadian Charter of Rights and Freedoms* *supra* note 10.

upon in a case involving government-funded health care for refugees, many of whom were poor women with medically in-need children.¹⁴⁰⁸

Section 12 of the *Charter* As Providing a Remedy

Section 12 provides that everyone has the right not to be subjected to any cruel and unusual treatment or punishment. Although uncommonly used in civil law, s12 infringement has been claimed in challenges to government decisions revolving around refusal to support vulnerable individuals.

I focus on s12 because the finding of a court that government's treatment of mothers of severely disabled children seeking support comprises cruel and unusual treatment would have significant impact. First, it would require government to revisit its law and policy in the areas I addressed in my thesis. Second, such a finding would relay to government that there was something amiss in its law and policy vis-à-vis international human rights norms (CEDAW, UNDRPD, UNDHR). Thus government would need to consider its international human rights obligations to severely disabled children and their mothers in light of its law and policy. Third, such a finding would be a strong statement from the court regarding the status of caregiving mothers and similarly of severely disabled children i.e. that they rank among those holding effective legal rights to support. Such a finding would serve to further the status recognition of mothers with severely disabled children, as mothers attempting to establish their legal rights through litigation. Presently their unique status as mother is either masked by the many myths about them and/or is ignored.

I commence by describing the legal test used to determine whether government conduct has infringed s 12. The test in Canada was set out in *R v Smith*, and considered recently in the civil context in *Doctors for Refugee Care*.¹⁴⁰⁹ In the civil context a key feature that must be shown is that those asserting their rights were infringed, came under government control.¹⁴¹⁰ Then it must be established whether their treatment meets the threshold of cruel or unusual treatment. This would establish a breach, and the test moves on to s.1. Then a court must inquire into whether the state is justified in causing the suffering that has been established.¹⁴¹¹ In order to provide an example of the test as applied to a case concerning government funding of needed care to a vulnerable group that included poor mothers and medically in need children, I turn to examine the facts of *Doctors for Refugee Care*.¹⁴¹² Then I also comment on the recent Supreme Court of Canada case *R v Boudreault* which has to do with criminal law that required

¹⁴⁰⁸ Canadian Doctors for Refugee Care *supra* note 902.

¹⁴⁰⁹ *R v Smith* [1987] 1 SCR 1045, 40 DLR (4th) 435; *Doctors for Refugee Care supra* note 902.

¹⁴¹⁰ *Doctors for Refugee Care, supra* note 902 at para 610. The key elements that support the finding of breach of s12 with respect to the 'policy' to end care, in *Doctors for Refugee Care* were (1) unusual circumstances and (1) to whom such action was directed and (3) the presence of administrative control affecting (4) nature of the treatment.

¹⁴¹¹ *Doctors for Refugee Care, supra* note 902. See Justice McTavish's opinion at para 1079.

¹⁴¹² *Canadian Doctors for Refugee Care* note 902.

impoverished offenders to pay money to the state pursuant to a mandatory victim surcharge levied against them as part of the conviction for summary and indictable offences.¹⁴¹³

Doctors for Refugee Care involved a challenge to federal government cuts to the Interim Federal Health Program (IFHP), which provided funding for refugee health care.¹⁴¹⁴ In making its determination the court inquired into whether the program in question was a “benefit”. It determined that it was.¹⁴¹⁵ This meant that the IFHP was subject to government regulation, as were those people who relied upon it. In applying the test to the facts, the court held that cutting funding to this population constituted treatment within the meaning of s 12 of the *Charter*. The treatment was also found to be cruel.

In determining what was ‘cruel’ treatment, the court noted treatment that was illogical and unjust,¹⁴¹⁶ and treatment that was degrading to human dignity and worth were cruel.¹⁴¹⁷ Using examples of health care refusal to child refugee claimants provided in evidence, the court opined that penalizing a child in need of care was an ineffectual and unjust way to deter a parent.¹⁴¹⁸

Doctors for Refugee Care held that, “cruel and unusual treatment or punishment must be drawn from evolving standards of decency that mark the progress of a maturing society.”¹⁴¹⁹ Various considerations may be taken into account, such as whether treatment goes beyond what is required to achieve a legitimate government aim; whether there were alternatives; whether it was arbitrary or had a social purpose; whether the treatment is unacceptable to a large segment of the population; whether it accords with notions of public decency or propriety; shocks the general conscience, or is unusually severe and hence degrading to human dignity and worth.¹⁴²⁰ Further, the court noted that the treatment in this case was not in compliance with the UNCRC,¹⁴²¹ nor compliant with the best interests of the child standard in domestic law.¹⁴²²

While government argued that “difficult and potentially unpopular choices have to made” at times,¹⁴²³ the Federal Court nonetheless held that the government cuts to care for this vulnerable group

¹⁴¹³ *R v Boudreault* 2018 SCC 58 CanLii

¹⁴¹⁴ *ibid* Canadian *Doctors for Refugee Care* *supra* note 902.

¹⁴¹⁵ The court enumerated the criteria that other courts have used in their analyses as to what comprises treatment in the past. *Doctors for Refugee Care*, *supra* note 902 at para 604.

¹⁴¹⁶ *Doctors for Refugee Care*, *supra* note 902 at para 668 referencing *Weber v Aetna Casualty and Surety Co.*, 406 U.S., 164, 175 (1972)

¹⁴¹⁷ *Doctors for Refugee Care*, *supra* note 902, at para 686 referring to *R v Smith* at para 44

¹⁴¹⁸ *ibid*, referencing *Weber* *supra* note 1243 at para 668.

¹⁴¹⁹ Justice Mactavish relying on *R v Smith* [1987] 1 SCR 1045, 40 DLR (4th) 435 *supra* note ##, referenced in *Doctors for Refugee Care*, *supra* note 902 at para 612, citing *Trop v Dulles*, 356 US 86 at 101 (1958).

¹⁴²⁰ All of which are derived from *Smith* [1987] 1 SCR 1045, 40 DLR (4th) 435 ref’d in *Doctors for Refugee Care*, *supra* note 902 at para 614.

¹⁴²¹ *Doctors for Refugee Care* *supra*, note 902 at para 660

¹⁴²² *ibid*, note 902 at Para 661

¹⁴²³ *ibid* at para 86

were not ‘saved’ by s 1.¹⁴²⁴ This resulted in a finding that government action breached s12, a decision upheld by the Federal Court of Appeal.¹⁴²⁵

In 2018 in *R v Boudrealt* the majority of the Supreme Court of Canada decided that a mandatory victim surcharge that was levied upon offenders, including those who were extremely impoverished and disabled individuals met the test for *punishment* and not only treatment.¹⁴²⁶ The court reasoned that although the sum of money of the victim surcharge set out in the impugned provision was not a significant amount for many Canadians to pay, it was nevertheless far beyond the means of many of those individuals being charged and convicted, especially as the court noted, they were grappling with addiction and mental health and other disability related issues¹⁴²⁷. The decision notes that many of those individuals were forced to return to court repeatedly to explain that they were unable to pay the required amount. The Supreme Court of Canada opined that this process amounted to “a public shaming” of offenders who were unable to pay.¹⁴²⁸ These features were decided to comprise a significant impact on the offender’s liberty and security interests and as such the surcharge was found to be grossly disproportionate. Even though the court opined that the bar demonstrating a breach of s 12 was set high, and even though it was only on rare occasions that a sentence infringes s12, it held the surcharge to be cruel and unusual punishment.¹⁴²⁹ The *Beaudrealt* court seemed to be swayed by socio-economic and disability related arguments pertaining to the unconstitutionality of a money-related punishment. The court also made reference to valid alternatives to this surcharge. It was not the only avenue open.

Applying s12 to State Support of Mothers with Severely Disabled Children

As shown in my thesis, government benefits are likewise a crucial source of support to mothers with severely disabled children. The literature review and legal research in my thesis revealed this dyad to be vulnerable and disadvantaged in the area of needed care. This reality mirrors *Doctors for Refugee Care*.¹⁴³⁰

As with the refugees in *Doctors for Refugee Care*, in seeking benefits, caregiving mothers fall under one form of government control or another. In reality, as my research revealed, they often fall under *many* forms of it, not just one, as was the case in *Doctors for Refugee Care*. Moreover it can be argued that the very nature of these supports forms part of what is cruel about the treatment of mothers needing them. For example, the hit and miss nature of support described by policy scholar Michael Prince and

¹⁴²⁴ Pursuant to the test as set out in *R v Oakes*, [1986] 1 SCR 103, 53 OR (2d) 719.

¹⁴²⁵ *Canadian Doctors for Refugee Care supra*, note 902.

¹⁴²⁶ *Boudrealt supra* note 1419 at para 40

¹⁴²⁷ *Ibid* note 1419 at para 77

¹⁴²⁸ *Ibid* note 1419 at para 77

¹⁴²⁹ *Ibid* note 1419 at para 45

¹⁴³⁰ *Doctors for Refugee Care supra* note 902.

legal scholar Lorne Sossin, and the weak or non-existent accountability of government in relation to the supports.

As noted above, the test used for infringement of s 12 provides that “cruel and unusual treatment or punishment must be drawn from evolving standards of decency that mark the progress of a maturing society.”¹⁴³¹ One can argue that the alternating indifference and harsh treatment of mothers with severely disabled children by a succession of provincial governments, over a now lengthy period of time, is both cruel and unusual. These two features (indifference and harshness) were apparent in legal cases I examined, in the important 2005 Ombudsman’s Report, in various media reports and in what is a growing body of research about the negative health effects under-supported care has on caregiving mothers and their children. Indeed, this was the consistent thread running throughout my research.

Having regard to the findings I have detailed about how caregiving mothers are treated in law and policy, which as noted run the gamut from indifferent to cruel, I presented scholarly literature from diverse fields concerning the circumstances of caregiving mothers. I also reviewed governments’ own reports on unmet needs of severely disabled children. These reports have often pledged to alter the status quo for the better. In spite of desperate caregiving mothers’ interviews in media pleading for help, their published narratives of continuing unmet need of care, their public protests about their untenable circumstances and government promises to do better, little changes. Mothers continue to be faced with levels of responsabilization that fail to adequately attend to their and their children’s lived realities.

Then there is their litigation, which also demonstrates the blatant disregard of women’s suffering, particularly evident in the way government has responded to the manifold and multifarious claims of caregiving mothers for needed support. As seen, mothers are met with strong government opposition, with complex litigation tactics and even (according to one judge) at times irrational,¹⁴³² and unreasonable approaches to their claims.¹⁴³³ Yet, in spite of this mothers continue to litigate, highlighting the very same issues. This was seen when Desmarais brought her application many years after Larcade’s case was decided by the Ontario Court of Appeal in 2006.¹⁴³⁴ This suggests again critical consciousness in legal action towards a shared goal, which in this case was to access state support.

The circumstance underlying this legal activity is mothers whose needs have borne the brunt of retreat from already inadequate or unavailable support and who are subject to almost continual changes in policy offerings, making such supports a moving target. This approach by government is disturbing, given the context of the claims, which involve very serious health and social care needs of marginalized children and their often socio-economically disadvantaged mothers.

¹⁴³¹ *Canadian Doctors For Refugee Care supra* note 902 # para 600.

¹⁴³² See for example *Dassonville-Trudel* 2004 *supra* note 1052 at para 38.

¹⁴³³ *Dassonville-Trudel* 2004 *Ibid* at para 38.

¹⁴³⁴ *Desmarais supra* note 950; *Larcade supra* note 207.

The threshold of s 12 requires “cruel and unusual treatment or punishment must be drawn from evolving standards of decency that mark the progress of a maturing society.”¹⁴³⁵ This very same question can be posed in relation to the kind and amount of care that mothers with severely disabled children are tasked with as a result of government action. For example, there is a growing body of research and also evidence from litigation that shows that the impact of complex forms of care is physically damaging to those mothers who provide it *in today’s care arrangements*. The literature I reviewed described this, underscoring how different the care which they provide is, and which I refer to as maternally complex care.

It is cruel that provincial governments have largely withdrawn from the provision of complex forms of care and support for mothers with severely disabled children. It is cruel that (for example) mothers across Ontario have had no choice but to leave their age of majority, disabled children at a government office.

It is also cruel that mothers have had no choice but to give up their minor children, ‘consenting’ to a stigmatized form of ‘care’ through the provinces’ child protection jurisdiction, when support for care is unavailable to them. On this issue, the deliberate conflation of ‘care’ with ‘wardship’ is a punitive and unjust ‘choiceless choice’ given to, and made, by caregiving mothers. A ‘choice’ made in spite of the associated legal and physical child loss. This form of government treatment relies on the myth of the failed caregiving mother to see it through. That is a cruel fiction. Canadian society moreover has already decided that institutionalization of severely disabled children is no longer acceptable.

An added argument may be made based on *Boudreault*, discussed above. That disabled offenders (those with psychiatric disability, addiction and other disabilities) were found to have been treated (punished) in a manner that violates s 12 raises some relevant points. The opinions expressed about punishment in *Boudreault* resonate with the way the government treats mothers who cannot afford to support their severely disabled children and are as a result forced to relinquish custody of them children to state child protection authorities. *Not being able to afford to pay* for care has parallels with being unable to pay a small surcharge. Arguably this too comprises public shaming during that legal process (in addition to the trauma of child loss). It has been experienced as punishment by mothers who have been on the receiving end of an unwanted child protection finding, when the issue was actually one of unaffordable (for them) child health care. It is widely seen as shameful and publicly humiliating to have a child taken into state care.

Considering the many problems with supports to mothers with severely disabled children, a court ought to consider the research discussed in my thesis, which found a number of disturbing health effects. One was the earlier death of caregiving mothers. Another was more frequent illness in the context of

¹⁴³⁵ *Canadian Doctors For Refugee Care supra* note 902 para 600.

extraordinary levels of care that are the result of inadequate support arrangements and which my thesis shows the government has itself reported on in its own statistical research. The suicides, attempted suicides and filicides reported in media and reviewed in the thesis, comprise another outcome that arises in the context of present, cruel, under-supported care arrangements. Together these features of caregiving mothers' lives should be factored into judicial consideration of what is cruel treatment. The remaining question after finding s 12 is violated in analysis under s 1, is whether the state can establish it is justified in causing the suffering that has been established in the cases I examined as well as in the literature.¹⁴³⁶ Government bears the onus of proof under s 1 of the *Charter*.¹⁴³⁷

A successful s12 claim, could lead to provincial governments changing their approaches to disability support policy, including how it affects mothers, and how it harmfully assumes their unremunerated support of disability writ large. By writ large, I refer to mothers' provision of all kinds of supports to disabled children, youth and adults of all ages. This makes the point that even unsuccessful cases can lead to desired policy changes.¹⁴³⁸

I have shown that governments' ableisms imposed on mothers are likewise cruel. Section 12 of the *Charter* provides a base upon which the many aspects of government policy can be brought to court in order to allow mothers with severely disabled children to legally realize their right to support.

Legal Remedies – The Status Quo

I have shown in my thesis that caregiving mothers have legal rights. I have shown they have the right to bring claims for support under certain statutes. I have shown that they have the right to apply for and to receive government benefits if they are eligible. I have also described legal rights under human rights codes that apply to their lived circumstances as mothers with disabled children. I have explained that

¹⁴³⁶ *Doctors for Refugee Care*, *supra* note 902 at para 1074 (4) the court opines as to the lack of justification on the part of government.

¹⁴³⁷ Section 12 has arguably already proven useful in the face of harsh provincial support policy in the civil law context. In *Rogers*, an Ontario criminal court found pregnant and clinically depressed Kimberley Rogers guilty of fraud in her receipt of social assistance, even though she did not know about reporting required concerning a benefit. Once found guilty, the court terminated her benefits and placed her under house arrest in appalling circumstances. Murray Campbell (15 October 2002) "Inquest to Probe Why Woman Cut from Welfare Died" *The Globe and Mail*. Online < <https://www.theglobeandmail.com/news/national/inquest-to-probe-why-woman-cut-from-welfare-died/article757173/> > In light of this treatment, a *Charter* claim was brought asserting that Rogers' s12 rights were infringed. Rogers however committed suicide, and her *Charter* case did not continue. Notably after the *Rogers* case, in 2004 the newly elected government of liberal premier Dalton McGuinty ended the policy of lifetime suspension of welfare benefits. Ontario government changed its policy. Murray Campbell (29 April 2004) "Liberals Shouldn't Forget the Disabled" *The Globe and Mail*. online < <https://www.theglobeandmail.com/news/national/liberals-shouldnt-forget-the-disabled/article743287/> >. See *R v Rogers* and *Rogers v Sudbury (Administrator of Ontario Works)* (2001), 57 OR (3d) 460, [2001] OJ no 2167.

¹⁴³⁸ Not only after *Rogers* did policy change, but also after *Auton* too *Auton* it will be recalled was a case concerning funding of supports to autistic children and their parents. Litigation in this regard can be seen to play a role in social change. *Auton supra* note 1139.

there are obligations on Canada under international human rights law that should be considered in government decision-making concerning mothers with severely disabled children. Also I have provided examples of mothers seeking remedies in administrative law, tort law and constitutional law.¹⁴³⁹ However, in spite of the above, my research found that litigating mothers were often unable to realize their legal right to support for a number of reasons. Teasing out the reasons was a focus in chapters four, six and seven.

At the outset, I asked: what are the legal rights to support of mothers with severely disabled children and what should they be. I further asked what are the legal rights of children with disabilities to state support and what should they be. In addition, I asked how the legal rights of the severely disabled child ‘fit’ with the legal rights of mothers to public support within existing frameworks.

I found that although there were recognizable claims, realizing their rights to support with their factual realities was fraught with difficulties. One difficulty was that their support claims were greater in scope and different in kind than provisions in both private and public law anticipated. Another difficulty was that some of the mothers’ other claims were not recognizable by the court. Their claims and the reality of their lives seemed to fall outside all legislation that might pertain to the support under discussion. While mothers sought to remedy the gaps and barriers with the realization of their support rights politically, little changed. This was seen in the advocacy and then litigation surrounding the *Larcade* case.¹⁴⁴⁰ Neither s 15 nor s 7 anticipate claims by mothers with severely disabled children and shoe-horning their rights to support into s 15 or trying to have courts read them into s 7 poses challenges.

Having referred to areas of law that described caregiving mothers’ situation, the legal remedies they might use to try to realize their legal rights to support, and the deficiencies in doing so, I proposed that s12 of the *Charter* could provide an opportunity for caregiving mothers to pursue a claim for infringement of their constitutional rights and briefly discussed how that claim could be approached.

In Conclusion

My research questions asked (i) what are the legal rights of mothers of children with severe disabilities to state support in Canada? (ii) What should the legal rights of mothers of children with severe disabilities be? (iii) What are the legal rights of children with disabilities to state support? And (iv) how do the legal rights of the child with a disability fit with the legal rights of mothers to public support within existing frameworks? Having undertaken research in the relevant areas of support law and policy, I considered what would be a more just alternative to the state supports currently available to mothers under primarily provincial, but also federal, law in Canada.

¹⁴³⁹ *Larcade* *supra* note 207; *Harris* *supra* note 1399 *Coates*, *supra* note 871 and others.

¹⁴⁴⁰ *Larcade* *supra* note 207.

In order to do that, as stated in this final chapter, I first described the rights examined in my thesis. I then revisited the literature review, highlighting in this chapter some of the scholars and how their work informed my thesis. In referring back to their work in *this* chapter, I provide an explanation of how *my* research and analyses contribute to and build upon the body of scholarly work that preceded it, in particular focusing on those whose work informed my own.

Subsequently, I provided a summary of my research findings. It revealed that even where caregiving mothers have legal rights, they find realizing such supports difficult or impossible. The reasons for this were described. This section also revealed the tremendous shortfalls and gaps in support offerings that require mothers to perform forms of extraordinary care. These in turn carry numerous burdens, many of which have not previously been examined in this context. These burdens of care are described as being harmful in many ways.

Following on that I analyzed legal remedies potentially available to mothers with severely disabled children and their shortfalls. These were administrative law, tort law, human rights codes, international human rights law and constitutional law.

This chapter ended with a brief analysis of how s12 of the *Charter* might be employed to encourage the state to re-consider its present woeful approach to the support of mothers with severely disabled children. This section, along with those that preceded it, reveals that the rights of caregiving mothers are next-to non-existent, where they should be automatically available. Their children's rights are lacking and excluded where they should be adequate and integrated. Further, their children's rights did not fit with the rights of their mothers, as the existing support frameworks in law and policy ignore the particulars of their support needs as well. In sum, as caregiving mothers Tolmie and Bachmeier stated, the government supports as currently structured *increase* maternal burdens.¹⁴⁴¹

Having examined numerous cases and considering rights in the ways I describe, I conclude that although mothers with severely disabled children do have different avenues along which to pursue support, any 'rights' they are thought to have often fail along a range of different fault lines. Cases examined shone a light on these fault lines, showing that rights to support are subjected to weak accountability and frank opposition. I interpreted this as the failure of the state to respect these rights. What rights to support there are, are inadequate. To be adequate, their rights must be tied to actual needs. In spite of maternal activism and litigation, the system of supports has not changed and unjust care burdens of many kinds persist.

¹⁴⁴¹ Tolmie and Bachmeier, *supra* note 967.

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Appendices

Appendix A: Canadian Blogger. Life with a Severely Disabled Child

My Prayer

In this moment I accept that I have been given care of a very fragile person.

I accept that I may likely never know why this task has been passed to me.

In this moment, I accept that I need not know more than the fact that what I do has value.

With that, I will care for this person to the best of my abilities.

I will forgive myself for the days I could do better, but don't.

I will forgive myself for the days I would do better, but cannot.

I seek to have clarity of thought that I might make choices most in balance with the many intertwining lives, including my own.

I seek to be supported in whatever ways financial and emotional that will maintain this balance.

I seek to learn how to draw from a well of infinite patience and energy.

I open myself up to the possibility of joy, of fulfillment, and of grace.

I accept that, in this moment, it is all I can do.¹⁴⁴²

¹⁴⁴² Claire (no last name), the blogger of *Life with a Severely Disabled Child*, *supra* note ##. She has an M.A. and a diploma in Montessori teaching. Her 2009 Blog entry is about problems with homecare in Ontario at the intersection of child welfare and SSAH (which she refers to as “homecare”). She quotes Ontario NDP MPP Cheri Di Novo that year as stating that the issue of insufficient support is one of political will.

Appendix B: Quotation from *Bowen v Gilliard* 483 U.S. 587 (1987)

In 1975, federal statutes governing the *Aid to Families with Dependent Children (AFDC)* program required, as a condition of eligibility, that applicants for assistance assign to the State any right to receive child support payments for any family member included in the family unit, but a recipient of aid (the amount of which is determined by the number and income of persons in the family unit) could exclude a child for whom support payments were being made from the family unit if it was financially advantageous to do so, even though the child continued to live with the family. The Deficit Reduction Act of 1984 (DEFRA) amended the *AFDC* program to require families to include in the filing unit all children living in the same home, including those for whom support payments were being received. Under a separate amendment, the first \$50 per month of child support collected by the State must be remitted to the family and not counted as income in determining its benefit level. Thus, if the assigned support exceeded \$50 plus the difference in the benefit level resulting from adding the child to the family unit, the family would suffer financially as compared with its total income prior to the amendment. In a class action, the Federal District Court held that North Carolina's implementing regulations were in conformance with the statute, but that the 1984 statutory scheme violated the Due Process Clause of the Fifth Amendment and its equal protection component, as well as the Takings Clause of that Amendment. *Bowen v Gilliard* 483 U.S. 587 (1987).¹⁴⁴³

¹⁴⁴³ In *Bowen v Gilliard* the court relayed the information that the standard of review was whether Congress had “a rational basis” for its decision and the United States Supreme Court decided that it did.

Appendix C: My son's school exercise book dated 1997

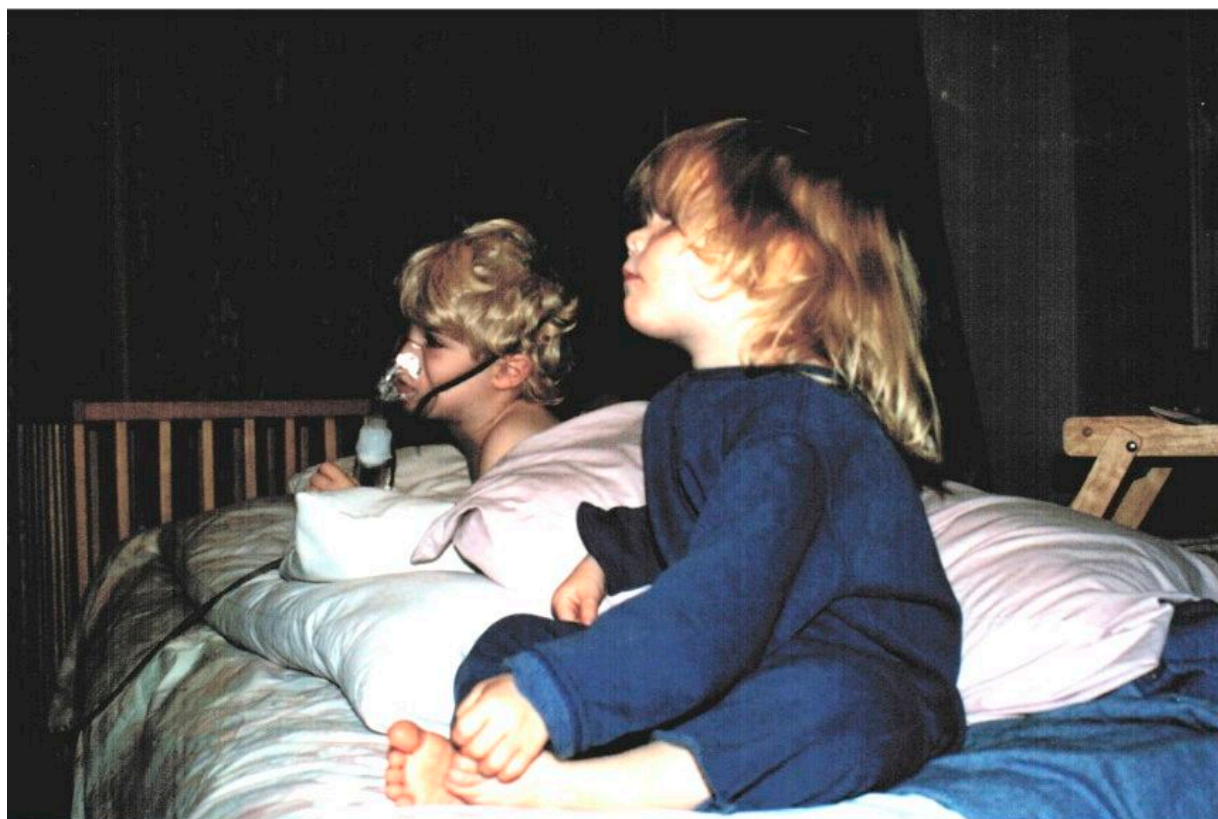
Monday Sept. 29/97

On the week end I had to go to the hospital because of my asthma. I was horking a lot. my throat was killing me.

I'm sorry to hear this Rory. I hope you are feeling better now.

Appendix D: Two of My Children

For years, several times a day and during the night, my (then) four year old son breathed with the support of mist produced from the ampules of steroids then ventolin with his nebulizing machine.





My eldest son, shown here at age eight, receiving an adult dose of intravenous anti-viral treatment for herpetic esophagitis, an uncommon life-threatening condition in immune compromised children.



At around age 6 a make-believe soldier incorporates his brothers' nebulizer mask.



In the bright NICU, I am allowed to hold my premature daughter who no longer required oxygen. She had sepsis and her chart stated her condition was guarded. I was a law student at the time and this was an exam week.





Appendix E: State Representation of Care

Princess Diana in Pakistan



1444

¹⁴⁴⁴ “Princess Diana Retrospective”, online: Gettyimages <<http://www.gettyimages.co.uk/detail/news-photo/princess-diana-princess-of-wales-cradles-a-sick-child-news-photo/76214656>>. This child is reported to have died shortly after this photograph was taken.

Duchess of Cambridge Kate Middleton in Alberta



1445

¹⁶³⁰ Rebecca English, “The Little Girl Who Didn’t Stand on Ceremony: Six-Year-Old Cancer Sufferer Flings Herself into Kate’s Arms for a Hug”, *DailyMail* (8 July 2011) online: Daily Mail <<http://www.dailymail.co.uk/news/article-2012370/Duchess-Cambridge-Kate-Middleton-embraces-cancer-sufferer-Diamond-Marshall.html#ixzz3ylrJ81PT>>.

Trina Pelletier and the Queen in Brantford, Ontario in 1973



1446

¹⁴⁴⁶ Mary Ormsby, "How I Met the Queen: Trina Pelletier, an Easter Seals Ambassador, Still Has the Dress She Wore", *The Star* (25 May 2012) online: The Star
<http://www.thestar.com/news/world/royals/2012/05/25/how_i_met_the_queen_trina_pelletier_an_easter_seals_ambassador_still_has_the_dress_she_wore.html>.

Appendix F: March of Dimes “Marching Mothers”



40,000 mothers marched. “Marching Mothers” is a registered Trade Mark. Canada’s first female federal cabinet minister was honorary leader of the March of Dimes campaign.¹⁴⁴⁷

¹⁴⁴⁷ “Marching Mothers”, online: March of Dimes

<<https://www.marchofdimes.ca/EN/AboutUs/about%20modc/history/Pages/marchingmothers.aspx>>.

Appendix G: Preamble to the Alberta Family Support For Children with Disabilities Act

Preamble

WHEREAS the people of Alberta honour and respect the dignity and equal worth of children with disabilities;

WHEREAS the Legislature of Alberta recognizes and values the ability of families to care for and to promote the development of children with disabilities;

WHEREAS the Legislature of Alberta acknowledges the value of family-centred support and services in empowering and preserving families of children with disabilities;

WHEREAS the Legislature of Alberta recognizes that the individual needs of children with disabilities are most effectively met through an integrated and multi-disciplinary approach; and

WHEREAS the Legislature of Alberta recognizes the importance of facilitating the inclusion of children with disabilities in community life:

THEREFORE HER MAJESTY, by and with the advice and consent of the Legislative Assembly of Alberta, enacts as follows: ...

Appendix H: Dr. Nicole Desmarais, in December 2014



APPENDIX I: Letter to Prime Minister Rt Hon David Cameron MP from Jane Raca

10 Downing Street
London
SW1A 2AA
9 December 2013

Open Letter (by email and post)

Dear Prime Minister

I am the mother of a severely disabled child. He has cerebral palsy, epilepsy, learning disabilities, challenging behaviour, and is severely autistic. He uses a wheelchair, can't walk or talk, can't use his left hand and is doubly incontinent. I am writing to you to express my concern over the lack of social care provision for children like him.

Many local authorities are failing to provide respite and home carers, and this is causing great suffering. There are parents trying to survive for years, raising their children on little sleep, with no breaks and no help. They are experiencing depression, exhaustion and marital breakdown. They have no hope of affording the ongoing specialist care which is needed. If they can summon the strength to take on their local social care department, they face a lengthy, ineffectual complaints process. What they need is a fast, independent forum, with the power to award the necessary support for their child.

The children and families' bill misses a golden opportunity to achieve this. It introduces joint education, health and care (EHC) plans in place of statements of special educational needs. For the first time parents will have all their disabled child's needs recorded in one place. But they will still only be able to appeal the education content of the plans to an independent tribunal, as is the case now. That happened to my family; we won an appeal over my son's school, but it took us another five years to get the social care he needed. Why can't the bill provide a right of appeal to tribunal, over all the contents of EHC plans?

The government has said that it doesn't support a right of appeal against social care issues. It doesn't want local authorities to be under a statutory duty to provide the care part of individual EHC plans, since they may not have enough money to look after both disabled children and children at risk.

This is the finite resources argument, and goes to the heart of the matter. We define ourselves as a society by the priorities we choose. Surely these priorities include providing humane levels of support to people who from birth will never be able walk or talk, let alone work? This should not have to be at the expense of protecting children at risk of abuse. Pitching those two sets of critical needs against each other is unacceptable.

The National Autistic Society has presented the government with a petition of over 10,000 signatures on the importance of a single point of appeal from all parts of EHC plans. That is a lot of parents, but it is also just the tip of the iceberg. They are telling you that they are not prepared to carry on battling on all sides. They need the EHC plans to make a real difference to the most vulnerable people in our society.

Yours sincerely

JANE RACA

Author Standing up for James