

'The Supports Exist- Why Can't We Access Them?':  
Unveiling the Barriers In Accessing Home Care Services for the Unpaid Caregivers of  
Children With Medically Complex Needs In Ontario

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### **Preamble**

My research question is born out of my lived experience as a mother to a child with severe cerebral palsy and deemed to be medically complex by Ontario's Ministry of Health and Long Term Care, Complex Care at the Hospital for Sick Children, and Community Care Access Centre (CCAC). Kian was born prematurely at 33.4 weeks and spent the first 21 days of his life in the neonatal intensive care unit. He had his first hospital admission at 4 months, and practically lived at the hospital for sick children for the first two and a half years of his life. Kian was identified as 'developmentally delayed' at 4 months old at which point the CCAC became involved to facilitate physiotherapy and occupational therapy until fall of 2014.

In the fall 2014, I stumbled upon an online support group through an article written by the parent of a child with a disability. This support group was my first time connecting with other parents of children with disabilities, and the first time I actually felt there was a community for my son and I. It was only through the support group that I learned about more services that CCAC had and that could benefit Kian. During the first few weeks after joining the group I read through previous discussions and it became apparent to me that parents were not able to access the home care supports their children required and were eligible for, specifically, personal support worker(s) (PSWs) and nursing care (RN/RPN).

The frustrating thing was that Kian had been with the CCAC for 2.5 years and I was never informed of the various home care supports he could access beyond physical and occupational therapy. With this new knowledge in hand I asked for a home

assessment to access a PSW in October 2014. I was offered 7 hours per week until Kian's temporary casts were removed, at which point he would no longer receive PSW support. At which point I asked: "Oh great, so when my son's casts come off, he won't be disabled?" We received a second home assessment and were allotted 10 hours of PSW per week. At this point, I had been a 24-hour a day caregiver for nearly 3 years and was frustrated and angry that the CCAC had not informed me that I was entitled to home supports that would aide us as a family. I researched the applicable health care laws and policies and called the Ontario's Ombudsman board to explain the frustration we had experienced as a family, the lack of information provided to us, the minimal level of service being offered by the CCAC, and what our quality of life was like as a family raising a child with Kian's medical complexities. Within 24 hours we had another home assessment, and within 4 hours of that completed assessment, Kian went from 10 hours of PSW to 30 hours of PSW per week plus 172 hours of nursing care per month.

Once Kian's services were established, I started to help other families' access home care supports. To date I have attended over 60 teleconference calls with families across 6 different CCACs in Ontario, attended over 30 meetings in person with 4 CCACs, and have successfully retained self-directed funding (SDF), sometimes referred to as self directed care (SDC), contracts for several families across the province. I have built networks with professionals from Local Health Integration Networks, the Ministry of Health and Long Term Care, the Office of the Minister of Health, and The Provincial Advocate Office for Children and Youth. I owe my abilities as an advocate to educating myself about applicable laws, policies, codes, and reviewing many case laws under the

Health Services Review Appeal Board, along with my lived experience as a caregiver for a child with medically complex needs. Some families are able to advocate for themselves, but many do not have the resources. These real life experiences and observations inform the Major Research Paper presented here.

I extend my gratitude to my Supervisor, Professor Farah Ahmad for her constructive feedback, review of multiple drafts, encouragement and patience. As well as, I am honoured to have received advising and critical guidance by Professor Marcia Rioux as my Advisor. I am grateful for both my sons for their continuous support throughout the entire MRP process. Additionally, my parents were the first who drove my passion for social justice and equity- through their own lived experiences and instilling those values in me. Finally, I am in debt to the parent-caregiver participants who entrusted me and shared their narratives about home care supports for their children with medically complex needs, informing this work in anticipation of improving Ontario's Home Care System.

### **Abstract**

Existing research, and my personal experiences and observations indicate that caring for a child with medically complex needs without formal support causes caregiver burnout. An additional layer of complexity relates to the duality of being both parent and caregiver, and societies' failure to understand how these intersect to cause undue burden on parents. The primary aim of the Major Research Paper is to examine why and how caregivers are facing these barriers in accessing home care supports in Ontario, along with the related health implications for children for their unpaid caregivers. This research is informed by the principles of critical social theory and emancipatory approaches along with human rights and intersectionality lenses. My comprehensive review of human rights frameworks demonstrated that rights to access home care supports are unequivocally established in international, national and provincial laws and conventions. In contrast, the qualitative interviews with ten caregivers of children with medically complex needs demonstrated several rights violations when accessing home care supports. The key findings include: negative impacts to caregivers' health due to difficulty accessing home care supports; withholding information resulted in unpaid caregivers being unable to trust CCAC staff; and the financial impacts of not having access to home care. Based on participant interviews, changes to the home care system need to include a proactive not reactive approach, and an emphasis on creating partnerships with unpaid caregivers in policy creation.

## **Chapter 1 - Background Research & Research Objective**

Research indicates that caring for a child with medically complex needs without formal support causes caregiver burnout (Cohen, 2012; Ontario Ministry of Health & Long Term Care, 2015). There is an additional layer of complexity related to the duality of being both parent and caregiver, and societies' failure to understand how these intersect causing undue burden on parents (Murphy, 2007). The intersection of inadequate services and attitudes towards responsibility for care of children with medical complexities creates an oppressive system. Home care services in Ontario began in the 1980s and have evolved due to technological advances that have allowed children with medically complex needs live longer lives, and shifted attitudes towards integration in the community through supported living. Yet, there remains limited scholarly research that looks at the socio-cultural and systemic difficulties caregivers of children with medically complex needs face accessing home care for their children in Ontario. Further, there continues to be a dearth of consolidated knowledge on home care policies and related legislations for medically complex children and their caregivers. I have observed first-hand the significance of these gaps and the need for urgency in addressing them to inform policy and practice.

### **Children with Medically complex needs in Ontario**

Children with medically complex needs are defined by Complex Care Kids Ontario (2016) as children who are technology dependent and/or are users of higher intensity care, are considered medically fragile, have chronic conditions (lasting more than six months), and medically complex needs (have at least five health care

practitioners/ health care services, or family circumstances that impede their ability to provide twenty-four hour care). At present there exists no public or compiled data on how many children with medically complex needs there are in Ontario, nor how many of these children access home care services.

The home care service sector has grown in the last twenty years in Canada and is provincially, not federally, funded. The growth of the home care sector is a result of the development of health policies supporting deinstitutionalization. This policy shift is heavily influenced by the technological advances which have increased the life spans of people with medically complex needs, allowing them to live at home with supportive care (Ontario Ministry of Health & Long Term Care, 2015).

### **Moving from Being a Parent to a Caregiver**

The medical model defines disability as the impairment or loss of function that impede the quality of life of individuals (Reyes, 2013). Whereas, the social model of disability defines disability as a socially constructed notion based in how society is organized, rather than an individual impairment or difference (Oliver, 2013). The social model has shown how removing the barriers that reduce life choices for disabled people, can allow people with disabilities to have a lifestyle equitable to their able-bodied peers (Reyes, 2013). Despite this, the medical model remains the dominant discourse. The tension between the medical model and social model of disabilities creates situations where a lack of understanding about the complexities in caregiving children who are medically complex results in unnecessary stress from barriers to accessing supports, stigma, and discrimination which affect both the child and parent (Reyes, 2013).

Caregiving has various labels in the existing body of literature. An informal caregiver, compared to a formal caregiver, is someone who is not paid for his/her caregiving role. Often various terms are used to refer to informal caregivers, such as 'unpaid caregivers,' 'parents,' or 'caregivers.' In this research paper, I use these labels interchangeably. This is because parents have intersectional identities with caregiving. A parent is defined as someone who is emotionally supportive, economically provides for, and overall plays an integral role in a child's development. Parenting a child with a disability intersects with caregiving and parents do not view their caregiving as a separate identity in relation to how they understand their roles. Further, the Ontario Home Care and Community Services Act recognizes the importance of supporting caregivers (i.e. parents/families/friends who are caregiving individuals who are disabled, medically complex, and/or elderly). The informal caregiving of children with disabilities has also been described as arrangements within families or wider kinship networks where the child is cared for long-term by a parent and/or by other family members or friends (Barrett, Hale, & Butler, 2014; Burton et al., 2008). The multi-layered needs of children requiring additional care leads to families finding different coping mechanisms, such as sharing caregiving roles (Burton et al., 2008).

The experiences of parents and/or families of children with medically complex needs are likely to vary overtime. When a child is born with a 'disability' or suffers an injury that requires additional care, parents and families experience a period of trauma and adjustment as they make the transition into their new roles as caregivers. Some scholars critique the focus on trauma as it draws from the medical model and neglects the

agency of children with medically complex needs and their parents (Racine et al., 2016). It has been noted that trauma can actually arise when physicians focus on the negative impacts of raising a child with a disability without much optimism and hope, and parents are actually more impacted by the lack of supports available for them than their children's disabilities (Racine et al., 2016).

There have been three key processes identified that a parent of a medically complex child goes through (Barrett et al., 2014; Green, 2007): The first is a grieving processes as the parents mourn for the child they thought they would have (i.e. the non-disabled child). This requires a reorientation to the new values of their culture, in particular, letting go of the idea within normative culture, that children grow up to be independent and build families. The moment a parent is given a diagnosis for their child, her/his role is shifted from being a parent to a caregiver. This realization stems from the reassessment of what it means to be a parent while also awakening to face a future of managing disability and care obligations (Barrett et al., 2014).

The second is a difficult period of ups and downs. These are periods of despair and uncertainty in how parents will care for their child in relation to the lack of supports and/or lack of financial resources available. Caregiver burnout often happens due to the hardships of adjusting to a new type of life with excessive caregiving duties and without home care supports in place. The stigma of disability and societal attitudinal barriers towards disability also creates down periods. Parents flourish and so do their child when the right supports are in place for their child in all settings (i.e. school, daycare, and home). The third is beginning a new life, where the focus is acceptance and dynamic

care. Adjusting to life as a caregiver is far from easy. There comes a time where parents reach acceptance and start being able to focus on their child's progress and how to best support/sustain their quality of life through caregiving tasks.

These three processes are deeply rooted in the emotional and personal dimensions of caregiving from the caregiver's perspective, as well as their development as caregivers (Barrett et al., 2014). These insights into caregivers' obligations and the positive impacts of supporting the quality of life of people with disabilities have led to the emergence of laws at the international, federal, and provincial levels. The human rights framework (alongside home care laws) is a part of the theoretical framework I am using to contextualize the ways in which the state is obligated to support caregivers, while taking into consideration how social identities shift over time and space, and these social processes will be analyzed through intersectionality which will be discussed in chapter 2.

### **The Impacts of Caregiving without Formal Supports**

Parents and/or families of children with medically complex needs have access to home care supports in Ontario. However, the majority of care work is undertaken by the parent/family caregivers themselves because of their dual identities as both parents and caregivers. Their caregiver roles require them to be available twenty-four hours a day, seven days a week with a high level of caregiving (Hanvey, 2002). All families have daily responsibilities, however, in addition to the daily activities that all families experience, the duties of parents of children with medical complexities can include: physically repositioning their children day and night, suctioning, G-tube (feeding through a tube into the stomach) and other methods of tube feeding, oxygen monitoring, heart

monitoring, administering medications, bathing, physically transferring, driving to medical appointments and therapy sessions, completing extensive paperwork, dealing with the stigma of disability, and personal mental health issues (Hanvey, 2002; Ward et al., 2014). The extra responsibilities from the high levels of care their children need can result in caregiver burnout (Ontario Ministry of Health & Long Term Care, 2015). The negative outcomes for caregivers include poor health (physical, mental, and social) and a decline in access to social determinants of health (e.g. employment) (Garg et al., 2015).

### **Caregivers' Health**

Caregiving has negative impacts on the health of caregivers when they have no formal supports, such as homecare (Dewan & Cohen, 2013; Murphy, Christian, Caplin, & Young, 2007). More than half of the caregiver participants in the study by Murphy, Christian, Caplin, and Young (2007) stated that their physical and emotional health was negatively impacted by the demands of caregiving. All the caregivers' experienced chronic fatigue, sleep deprivation, and back and shoulder pain (Murphy et al., 2007). Emotional distress amongst caregivers has presented as worries about stigma and children's future, anxiety, depression, posttraumatic distress disorder (PTSD), guilt or difficulties holding paid work (Dewan & Cohen, 2013; Murphy et al., 2007). Caregivers have rated their own health needs as the lowest priority and report experiencing barriers to addressing their own health needs due to a lack of time stemming from a lack of respite hours and qualified alternative care providers (Murphy et al., 2007). All caregivers occasionally experienced burnout, which they defined as overwhelming feelings of despair with no end in sight (Murphy et al., 2007).

### **Sleep Deprivation, Family Break Down, and Social Well-Being**

Parents of children with medically complex needs were reported to experience poorer sleep than parents of children without any neurodevelopmental disability or medically complex needs. Poor sleep is associated with developing poorer mental health and also has negative implications for social well-being. Additionally, it is well documented that children with various health-care needs experience poor sleep (Hysing, Sivertsen, Stormark, Elgen, & Lundervold, 2009; Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008; McCann, Bull, & Winzenberg, 2015; Wayte, McCaughey, Holley, Annaz, & Hill, 2012). In research conducted by Meltzer and Mindel (2007), it was determined that the child's quality of sleep is an indicator of the quality of the mother's sleep, and that mothers of children with complex needs have increased sleep disturbances compared to mothers of children without disabilities. One particular study focused on how sleep disturbance negatively affects daytime outcomes for parents (McBean & Schlosnagle, 2016) and in another study, poor sleep was associated with memory impairment as sleep is essential for information processing and memory consolidation (McBean & Schlosnagle, 2016).

Sleep deprivation in children has a direct negative impact on the sleep quality of their parents. Sleep deprivation was much higher with parents with children with medically complex needs due to the close monitoring their child requires at night (Bourke Taylor, Pallant, Law, & Howie, 2013; Brehaut et al., 2004; McCann et al., 2015; Meltzer & Montgomery-Downs, 2011). Parents also woke up to reposition their children (Wright, Tancredi, Yundt, & Larin, 2006), and attend to them if they were in pain or vomited

(Heaton, Noyes, Sloper, & Shah, 2006; McCann et al., 2015). The mother of a 17 year old with cerebral palsy expressed the anxiety and fear parents experience when she stated she was afraid “he may vomit, choke, and die” (Wright et al., 2006).

For parents of children with medically complex needs it is important to ensure their child’s safety overnight, and because of this, they are less likely to take sleeping pills because of side effects that can leave them feeling drowsy and less able to provide the extensive care their child requires (McCann et al., 2015; Steele & Davies, 2006). Furthermore, ongoing sleep deprivation of the child and the caregiver impacts the family’s ability to function, which in turn causes stress intolerance (Wei & Yu, 2012). These studies demonstrate how a lack of formal support in homes with children with medical complexities contributes to sleep deprivation and family breakdown.

### **Caregivers & Employment**

There is limited literature specific to caregivers of medically complex children, but inferences can be drawn from relevant scholarly work on caregivers of children with disabilities. Research has revealed that parents of children with disabilities have lower participation in the labour force and are more likely to leave altogether due to a lack of accommodation in workplaces and a lack of access to services to care for their children while they work (Brennan, et al., 2016; Crettenden et al., 2014; McConnell & Breitkreuz, 2014; Raina et al., 2005). An article by Brandon (2014) looked at how a mother’s short-term reduction in work hours or work hour negotiation was directly linked to raising a child with a disability. He noted that allowing mothers (who were the primary caregivers of the children with disabilities) to have flexible work schedules increases their economic

contribution. Brown and Clark (2017) completed a literature review of employed parents of children with disabilities and work family life balance and found that the inability to find suitable childcare contributed to their difficulty achieving work/family balance. A logical consequence of employment difficulties is financial strain and vulnerability to poor socioeconomic life situations. Brown and Clark recommend the creation of government funded, and quality childcare that meets the needs of children with disabilities. More research that considers the impact of unemployment on parents of children with disabilities/children with medically complex needs is needed.

### **Services Under the Home Care and Community Services Act, 1990**

Currently, under the Home Care and Community Services Act (1990), the professional services available for home care are: (1) nursing services (RN/RPN/NP), (2) physiotherapy, (3) occupational therapy, (4) social work, (5) speech-language pathology services, (6) dietetics services, (7) training for a person to provide such services in 1-6, (8) providing prescribed equipment, supplies, or other goods, and (9) services prescribed as professional services. Additionally, personal support services (i.e. Personal Support Workers) also fall into the Home Care and Community Services Act (2016). Personal support services include: (1) personal hygiene; (2) routine activities of daily living; assisting persons with any of the activities mentioned in (1) and (2); (3) training a person to carry out or assist with any of the activities mentioned in (1) and (2); (4) providing prescribed equipment, supplies or other goods, and; (5) services prescribed as personal support services.

The purpose of this study is to specifically look at shifting nursing and personal

support services as these services provide caregivers' relief and the longer-term services that meet the daily living needs of children with medically complex needs. As of October 1<sup>st</sup> 2015, nursing and personal support worker monthly allocation maximums are the following: Personal Support Worker (PSW) 120 hours for the first 30 days of service and 90 hours per month going forward; Registered Nurse (RN) is 230 hours per 30 days; Registered Nurse (RN) mixed with Registered Practical Nurse (RPN) is 258 hours per 30 days; and Registered Practical Nurse (RPN) is 284 hours per 30 days. The premise of this research paper is to review if these supports are being accessed, how are they being accessed, what barriers exist to accessing them – be they political, cultural, societal, and/or economic – and how parents/caregivers can overcome these barriers.

### **Research Objectives**

The overall goal of this major research paper (MRP) is to critically analyze, examine, and theorize the social, cultural, political, and economic barriers that children with medically complex needs and their families (i.e. parents/guardians as caregivers) encounter when accessing home care services in Ontario. *The primary aim of the research is to examine why and how caregivers are facing these barriers in accessing home care supports, along with the related health implications for children with medically complex needs and their caregivers.* My research is informed by human rights and intersectionality frameworks. The specific research questions for this study are:

1. Do children in Ontario with medically complex needs have the right to access home care supports?

2. What rights do caregivers (i.e. parents) of children with medically complex needs have to access home care supports?
3. Are the services (i.e. nursing and personal support workers) that currently exist within Ontario's home care system meeting the needs of the caregiver and the needs of the child?
4. What are the experiences of Ontarian's families with children with medically complex needs in accessing home care supports?
5. Is the dismantlement of CCAC (Community Care Access Centres) making, or will it make, an impact on service delivery for this specific population group?

These questions will be examined through focused critical literature review (question 1 and 2) and in-depth qualitative interviews (question 3-5) with parent-caregivers of children with medically complex needs.

## **Chapter 2 - Methodology & Methods**

The overarching research paradigm for this research is critical social theory (emancipatory) and the specific lenses to be applied are intersectionality and human rights frameworks. Kincheloe and McLaren (2000) state, "a critical social theory is concerned in particular with issues of power and justice and the ways that the economy, matters of race, class, gender, ideologies, discourses, education, religion and other social institutions and cultural dynamics interact to construct a social system" (p. 281). This resonates with my desire to address the powerlessness of caregivers and children with medically complex needs, especially in accessing home support care. In terms of

ontology, critical social theory argues for 'historical realism,' that reality is built socio-historically and values are crystallized overtime (Kincheloe et al., 1998). I believe that issues in accessing home support care are socially constructed and can be changed by generating new knowledge and giving voice to the concerns of the community. This aligns with the emphasis on individuals' agency and potential autonomy found in critical social theory. Epistemologically, critical social theory promotes social justice and opposes oppression, and values subjective knowledge and the role of researcher. I believe in universal access to health care and wish to unpack disparities in order to improve the health of caregivers and children with medically complex needs. Given that value-mediated knowledge generation is a key tenet of critical social theory, I believe that my role as a mother of child with medically complex needs and as a researcher enhances the overall research process (e.g. participant engagement), knowledge generation (e.g. analyses), and dissemination (e.g. policy briefs and community reports). Critical social theorists argue that oppression is reproduced by 'false consciousness' where people are socialized to believe that problems are not located in society but in individuals (Kincheloe et al., 1998). This research unpacks underlying assumptions and demonstrates the role of structures in determining access to home supports for caregivers of children with medically complex needs.

Further, the application of an intersectionality lens to the data allows a multi-layered understanding of marginalization and identity within society (McCall, 2005; Crenshaw, 1991). My review of human rights' frameworks unveils the rhetoric and

practice gaps in the provision of home support care. In the following section, I elaborate on emancipatory research, intersectionality, and human rights.

### **Emancipatory Research**

Research methodologies and methods for conducting research on disabilities have changed over time in response to the Disability Rights Movement which shifted discourses on disability and research from the abled-body to the disabled, “guided by the principle ‘nothing about us, without us’” (Oliver, 2002). Traditional research on disability has been critiqued due to its exclusion of people with disabilities in the research process (Oliver 2002; Petersen 2011). The disability rights movement called for disability theory, research, and law to be premised on first-hand knowledge and experience of disability (Charlton 1998; Petersen, 2011; Shapiro 1994).

Research about the lives of disabled people and their families has often created hierarchical power dynamics between researchers and participants (Oliver & Barnes 2008). Emancipatory research disrupts these dynamics and provides a framework for conducting a critical social approach to research *with* people with disabilities. Chappell names five principles in using qualitative data: “1. Research ought to be used as a tool to improve the lives of disabled people; 2. There should be greater opportunities for disabled people to be researchers; 3. Researchers must adopt a more reflexive stance regarding their work; 4. The democratic organizations of disabled people should act as commissioners and funders of research; and 5. Researchers should be accountable to the democratic organizations of disabled people” (as cited in Boucher & Fiset, 2015, p. 128)

What this approach highlights for my research is the important role that the caregivers of children with medically complex needs hold as knowledge producers, from the conception of the research questions to the analysis of the results (Boucher & Fiset, 2015). An emancipatory research approach challenges the power dynamics ensuing from my “authority” as a researcher and the voice of participants; thus, my aim is to give privilege to the voices of parents of children with medically complex needs.

An emancipatory framework guides the use of more equitable research practises that can lead to social change (Oliver & Barnes 2008; Petersen 2011). This can occur through providing space for individuals with disabilities by decentering the researcher as expert, and working in collaboration to determine and carry out the goals and aims of individuals with disabilities. Thus, I aimed to take an approach that reduces the power dynamics between participants and myself and chose qualitative interviews for data collection. I also believe that people are not empowered by other people, they empower themselves, and people with power (e.g. the researcher) can help by decentering themselves, listening, and creating space for the participants to speak.

Families and parents of children with disabilities and medical complexities have disrupted discourses of disability that have excluded them. Although they have been received as alienating or too protective of their children with disabilities, they have supported the ways in which people with disabilities want to live (Ryan & Runswick-Cole, 2008). The families and parents in my research collaborated with developing the research question when they kept telling me (in my role as advocate) they wanted to share their stories and wanted research on the barriers they have encountered to access

home care supports, specifically to do with children with medically complex needs. With their input and first hand lived experience they had a privileged position in informing the research questions, analysis and findings.

There are three essential principles that inform an emancipatory approach to research: *reciprocity, gain, and empowerment* (Oliver, 1992; Petersen, 2011). Reciprocity is “the researcher’s willingness to expose one’s vulnerability and mutually exchange personal information” (Petersen, 2011, p. 299). Thus, the interactions between the researcher and the participants is similar to a ‘two-way-street,’ as stories and information are shared between two people (Petersen, 2011). Furthermore, the researcher should listen to the needs of participants and endeavour to help in ways that are not directly related to the research. For instance, participants share their narratives and emotions, which is important information for the researcher, and in exchange, the researcher can provide participants with information that may help them. While I was conducting my interviews, I shared information pertaining to the informal and formal ways of appeal home care decisions, and who they could contact for additional support.

Research with people with disabilities often does not directly benefit participants, such as through improved outcomes, or more equitable access to services, resources, and education, which contribute to tensions between participants and researchers. Therefore, we need to understand how the principle of gain is understood in research. Petersen (2011) suggests “Research must be a practical benefit, must influence policy, and share critical and contradictory perspectives with a wide variety of stakeholders” p. 300). Thus, I placed emphasis on participant stories and narratives for the synthesis of findings.

In emancipatory research empowerment is defined as a process in which individuals empower themselves (Petersen, 2011). The purpose of the researcher should be to create the means for individuals to be able to exert their agency (Petersen, 2011). Working for and at the disposal of individuals with disabilities is what the emancipatory researcher must do (Petersen, 2011). This informed my process of data collection where I aimed to build mutual respect and genuine relationships by first sharing some of my experiences to encourage self-reflection and deepen their insight into their own situations.

There is often tension in what is valued in research, between what is considered academic rigour, and what is considered relevant and useful for marginalized individuals and social change (Petersen, 2011; Walmsey & Johnson, 2003). As a health equity researcher, I have an obligation to social justice. An emancipatory approach to research provides the framework for meaningfully including the voices of parents of children with disabilities directly into my research process, leading to the creation of theory and policy grounded in dialogue for social change.

### **Intersectionality**

Intersectionality is a feminist framework that supports the analysis of multiple intersecting oppressions (Crenshaw, 1991; McCall, 2005). It is a multi-layered understanding of identity and marginalization within society (Crenshaw, 1991; McCall, 2005). McCall (2005), a feminist scholar, examines the ways scholars can understand and use analytical categories to explore the complexities of intersectionality within social life. Intersectionality has led to three distinct approaches to categorizations: anticategorical complexity, intercategory complexity, and intracategorical complexity (McCall,

2005). Anticategorical complexity addresses the need to deconstruct analytical categories. It states that identities are far too complex to fit into static and distinct categories, and that identities contain deep complexities. The second is an intercategory approach, which proposes that academia adopt already existing social identities, rather than impose constructed identities to document conflicting dimensions of identity (McCall, 2005). In short, how different identities are affected differently by different structures in society. Finally, an intracategorical approach is the foundation for intersectionality. Intracategorical complexity understands that social identities are boundary making and have a boundary defining process itself. Additionally it recognizes the stable and lasting relationship that social categories represent at any point in time while maintaining a critical stance towards categories/identities (McCall, 2014). It is referred to as intracategorical because of the focus on how particular social groups are neglected at points of intersection. For example, a Black woman with disabilities, has three marginalized social identities, race, gender, and disability intersecting one another that increase or multiply the oppression that she experiences and intersect in different ways in different situations (McCall, 2014).

Within intersectionality theory, identities are complex, fluid, and non-binary. For example, my son who appears White has better access to health care than a Black child with disabilities due to racism in service provision. Whereas my child is marginalized when health care professionals treat him as a disability rather than as a human being with agency. Intersectionality acknowledges how interlocking oppressions are experienced depending on time and location (Hankivsky et al., 2012). Intersectionality provides

direction for researchers and decision makers to critically reflect and move beyond insular categories typically favoured in policy analysis (Hankivsky et al., 2012). It proposes a consideration of the complex relations between mutually constituting factors of social location and structural disadvantage to accurately map and conceptualize the determinants of equity and inequity (Hankivsky et al., 2012). Intersectionality is examined through reflexivity, relationality, processes of differentiation, and accounting for resistance/resilience (Hankivsky et al., 2012). Adding intersectionality into research is a political action due to its commitment to unmask the inequities of power relations that maintain inequity and generally remain unquestioned within dominant policies, laws, and research (Hankivsky et al., 2012). Furthermore, intersectionality pushes conventional methodologies that understand social relations in binaries, allowing rich analyses that can concurrently account for multiple systems of oppression (Griffin & Museus, 2011). In this paper I examine how parents of children with disabilities and medical complexities experience a (dis)connect between their social identities as caregivers and their personal identities as parents and the obligation to support their children. I will also explore how the social processes that result in inequitable access to home care services are in conflict with international, federal, and provincial laws.

Employing an intersectionality framework means I must question my privileged position as a researcher. Intersectionality allows for engagement in reflexive processes to understand the relationship between power and privilege. I have two distinct roles within this research domain, the first is as a researcher, and other is as a parent of a child with severe disabilities and medically complex needs. As a researcher, my role in society is to

produce knowledge and unmask the social injustices certain population groups endure through social processes (Griffin & Museus, 2011). However, I am also an active member of a community of parents and families with children with medically complex needs. As a community of parents, we have formed trusting relationships as we all strive to overcome the social and political hardships we encounter on a day-to-day basis, often working together for social change. In order to account for my dual role, I will engage in reflexivity during research. “Reflexivity includes continuous attention and reflection upon the social practices of positioning and differentiation in the field... as well as analytic reflection upon the importance of academic knowledge and processes for social and political struggles” (Carstensen-Egwuom, 2014, p. 273).

### **Human Rights Framework**

In order to understand how individuals’ intersecting identities impact their access to home care supports in Ontario, we need to look closely at applicable rights based frameworks. Human Rights are laws that protect individuals’ civil, political, economic, social, and cultural rights from birth. The United Nations (1948) outlines the basic principles supporting human rights as: (1) Universality: Everyone has access to human rights, without exception. All individuals are entitled to these rights by virtue of being human. (2) Indivisibility: Human rights are indivisible and interdependent. These rights are interdependent because governments have an obligation to ensure economic, social, and cultural rights are upheld in order to ensure that civil and political rights are upheld. These rights are indivisible because, for example, if a government violates a right such as access to healthcare, it affects the ability to exercise other rights, such as, the right to life.

(3) Participation: Individuals have the right to participate in how decisions are made pertaining to the protection of their rights by having input into government decisions, and governments must ensure engagement and support from civil society. (4) Accountability: It is essential that governments establish effective accountability mechanisms to enforce these rights. (5) Transparency: Governments must maintain openness in information and decision-making processes in relation to rights. Individuals must have access to knowledge to understand how public institutions (e.g. schools and hospitals) function. (6) Non-discrimination: Human rights are guaranteed without any level of discrimination including intended and unintended discrimination. This paper will be looking specifically at Children Rights, Human Rights, and Rights for Persons with Disabilities in Chapter 3.

### **Qualitative Interviews**

Qualitative interviews were chosen to answer the proposed research questions (i.e. 3-5, see page 11) as they enable participants and researchers to interact with one another, to build rapport and meaningful relationships (Creswell, 2014; Teddlie & Tashakkori, 2009). These relationships then allow the participants to share their experiences and perspectives even when the discussions involve difficult subjects including experiences of oppression, stigma and challenges. This method of data collection is compelling due to the opportunities for one-to-one interaction between researchers and participants that offer opportunities to ask for explanations to vague answers, and for participants to ask for clarification on questions (Kvale & Brinkman, 2009; Teddlie & Tashakkori, 2009).

I employed semi-structured interviews guided by open-ended questions that led to a more conversation style interview. “Open-ended interviews allow respondents to

express their understanding in their own terms” as “opposed to interviews with closed-ended items that force respondents to fit their knowledge, experiences, and feelings into the researchers’ categories” (Patton, 2002, p. 348). Semi-structured interviews, also allow for a considerable amount of information to be generated, which can lead to re-theorizing and re-conceptualization of the research problem. Insightful conversations can occur when using this type of method that lead to enriched knowledge production in research.

### **Participant Recruitment**

Parents of children with medically complex needs were eligible if they resided in Ontario and spoke English. Potentially eligible parents/guardians were recruited through: 1) online support groups; 2) word of mouth; and 3) the Office of the Provincial Advocate for Children and Youth.

I approached four closed Facebook groups: “Caregiving for Medically Complex Children in Ontario”; “Parents Advocating for Homecare System Change”; “Three To Be- PAL”; and “One More Thing”. Members of these groups are parents of children with medically complex needs and primarily reside in Ontario. Families can access advice on advocating for their children and themselves, and share information and experiences with one another about the home care system and other related aspects. I had access to these Facebook groups as a pre-existing member because I have a child who has medically complex needs. I posted the Study Information and Invitation sheet (Appendix A) to these Facebook groups; interested participants contacted me directly via email/private messaging through Facebook for details. I had further discussions with some of the participants on the phone to provide them with opportunity to discuss the research and

clarify any questions they had. Participants identified through the Facebook groups were asked to share the study information, by word of mouth, using the Study Information and Invitation sheet (Appendix A) with other potential participants. I also circulated the Invitation sheet through email and in-person within my social network of parents/guardians of children with medically complex needs. My research participants fall within the definition of “hard-to- reach participants,” a population with low numbers making the potential pool of participants smaller, and members of this population group may be difficult to identify and may not want to disclose their membership in this population group due to social stigma (Baltar & Brunet, 2011; Browne, 2005). Word of mouth method allowed for recruited participants to share the information within their networks, accessing a larger potential participant pool (Baltar & Brunet 2011; Browne, 2005; MacDougall & Fudge, 2001). Finally, The Office of the Provincial Advocate for Children and Youth was approached via email and I requested them to distribute the Study Information and Invitation sheet as appropriate.

Potential participants who contacted me were provided with the study details contained in the Informed Consent Form (Appendix B) and assessed for eligibility. Eligible participants were invited to participate in in-person, one-to-one interviews or focus group discussions organized at a mutually convenient time. However, due to timing and personal obligations of participants, all interviews were individual based.

Overall, nine phone interviews and one in-person interview were conducted and audio recorded. Most parents preferred over the phone interviews due to time and commute constraints in relation to their life and caring for their child(ren) with medically

complex needs. Participants electronically received the study information and informed consent form before the interviews. They were provided more details before the actual interview and expressed consent. I used both verbal and written consent as it allowed participants to decide in which way they felt safest giving consent (Denzin & Lincoln, 1994; Palmater, 2011; Petersen, 2011; Ritchie et al., 2013). There have been studies conducted where oral consent was preferred, because it reduced participants' mistrust and perceptions about risk of exploitation by a researcher (Denzin & Lincoln, 1994; Petersen, 2011). Oral consent allows for the participants to have agency over what kind of consent they want to provide and what personal details they want to provide. It was important for me as researcher to make the participants feel as safe as possible and for them to do what is within their comfort. Eight of the ten participants provided written consent, and all 10 participants provided verbal consent, which was recorded using an audio recorder. Additionally, seven out of the 10 participants completed a brief demographic survey (Appendix C) with some questions on home support services; tables of the data from the descriptive survey are in Appendix D. Each participant was also provided with a list of resources (Appendix E) pertaining to Ontario Home Care Supports and Appeal Information websites. During interviews I provided participants with information on appealing home care support decisions in Ontario.

The semi-structured interviews contributed rich data and allowed for flexibility to comprehensively explore and understand the barriers parents were encountering. The discussion topics in the interview guides (Appendix F) asked about experiences of accessing home care supports; experiences of appeal processes; societal and cultural

barriers; economic and political barriers; and future recommendations. The semi-structured nature of the interviews allowed me to gain several additional insights. I also made reflexive notes before, during and after the interviews. The collection of data from ten interviewees and my ongoing reflections advanced my understanding from a more holistic perspective and revealed cross-cutting and systemic issues.

### **Interviewing and Transcription**

As a graduate student in Critical Disability Studies I am interested in how meanings are produced and reproduced within particular social, cultural and (inter)relational contexts. I understand that interviewing is one means of interactive meaning-making and interpreting qualitative data requires reflection on the entire research process (Kvale & Brinkman, 2009; Palmater, 2011). Reflexivity involves making the research process itself a focus of inquiry, revealing my pre-conceptions and becoming aware of the situational dynamics in knowledge production in which the participants and I are jointly involved (Palmater, 2011).

The findings in research are not only constructed at the end of the research, but rather throughout the entire research process itself (Lord & Hutchison, 2002). In my research, emergent findings from one interview informed subsequent interviews and analyses. Being reflexive provided me with the opportunity to revise questions and re-frame the research topics to respond to the information I was soliciting as the research unfolded (Kvale & Brinkman, 2009; Lord & Hutchison, 2002). In my study, this occurred when participants shared other important information on their own that was not already addressed in my questions, because they wanted me to know more. Most of this

information was extremely helpful and led to more questions for further clarification. According to Lord and Hutchinson (2002) ongoing analysis during interviewing also entails examining the dynamics of the interview, and when a participant does not say something it can be just as revealing as what was said out loud. During interviews there were instances of silence, and in my view, it was often a moment of reflection about the conversation for the participant and myself. They only lasted a few moments but there was something very telling about the participant emotion and relief of being heard as they all had anguish due to difficult experiences accessing the home care system. Nine of the ten participants encountered many barriers to access the supports they currently have and “everything is a fight” as one participant said. Through reflection I identified previously unacknowledged preconceptions, and made revisions for the next round of interviewing.

Even when it was not feasible to conduct another set of interviews, interviews with serious gaps in communication or misunderstandings between the interviewer and respondent still provide important opportunities for learning (Palmater, 2011). There were times where the participant and myself experienced difficulty keeping an objective agenda and we had honest, raw conversations because I am well known and trusted in this community. I kept a diary to capture these observations and moments of reflexivity.

All interviews were transcribed verbatim and data analyzed thematically using constant comparison techniques within and across the interviews (Creswell, 2014; Kvale & Brinkman, 2009; Teddlie & Tashakkori, 2009). Once interviews were transcribed they were sent back to the participants to review before analysis. This allowed them to have an opportunity to look over their interviews to see if there was anything they no longer

wanted to share, to add, or for it to remain the way it was. This allowed for collective process to build knowledge together and for the participants to have an active role in the research process. None of the participants redacted any of their interview information.

### **Data Analysis & Thematic Analysis**

Conducting data analysis within qualitative research is a form of narrative, a story to be shared with the reader (Taylor & Bogdan, 1998). The convergence between storytelling as literary writing, and data analysis within qualitative research is how my writing can embody the experience of the participant so the reader can walk in the participants' shoes. While trying to show the reader what life may be like for the participant I am also building theoretical insights. My theoretical insights are on the intersections of societal discourses, social identities, and the political, economic and cultural barriers that create the inequities unpaid caregivers experience accessing home care supports in Ontario. In order to develop theoretical insights then, it is important to understand the elements of social life beyond individual experiences and to look carefully at the environment (Taylor & Bogdan, 1998).

Qualitative researchers' use analytic induction to develop and verify questions about society and social processes (Kvale & Brinkman, 2009; Taylor & Bogdan, 1998). Qualitative data analysis is an intuitive and inductive process and most researchers analyze and code their own data, first identifying themes and developing concepts and propositions. While conducting in-depth interviews I was constantly theorizing and trying to make sense of the data. For example, after a conversation on an interview topic I would verbally summarize what the participants told me which allowed an opportunity

for them to add, correct, or change anything they said or anything I misunderstood. I used a semi-structured interview guide but rephrased the open-ended questions and used probes if the participants were unsure. The interview topics (and questions in a topic) were introduced based on the flow of conversation and it became apparent during interviews that participants were very much empowered by the process of telling their own narratives in the way they wanted to share them, and shared whatever information was important to them. As I was conducting my interviews I was scribbling down notes while actively listening to the participants. During interviews I reflected and was attentive to my reflections on what I was hearing. For instance, one participant stated, “without caring for my son he would die”. This statement struck many emotions in me because I am the mother of a child with severe disabilities and medical complex needs, but because I was a researcher I needed to write down this quote to remember for further analysis. Throughout each interview concepts and themes were constantly emerging and shifting in a fluid and developing process.

Part of my analysis involved re-reading all transcripts, documents, and materials pertaining to my research so that I knew my material inside and out. Once the data was collected and transcribed it was coded for dominant themes using an on-going comparative technique, which led to constantly processing my understanding of the focus of my research (Taylor & Bogdan, 1998). Typologies were a helpful tool and helped me locate important themes in addition to developing concepts and theoretical insights (Taylor & Bogdan, 1998). For instance, I developed themes in relation to concepts I found from the interviews I conducted. Additionally, I looked at how they were

interconnected through intersectionality theory and human rights lens. Some of the concepts I found in my research were space and time, power, equity, gender relations, language barriers, educational background, income, family status (i.e. single, married), and social identities and how these were intersectional.

### **Chapter 3 - Analysis**

Chapter 3 has two parts. Part A is a review of relevant human rights frameworks at the international, national, and provincial levels, and the current home support care experiences of the caregivers reported in the literature, and in my interviews with participants. Part B presents findings from my analysis of the interviews with caregivers of children with medically complex needs.

#### **Part A - Review of Human Rights' Laws and Conventions**

The aim of this review is to answer two particular questions: (1) Do children in Ontario with medically complex needs have the right to access home care supports? (2) What rights do caregivers (i.e. parents) of children with medically complex needs have to access home care supports?

**Human rights.** The Universal Declaration of Human Rights (UNUDHR) was established by the United Nations in 1948. The Declaration outlines international laws that protect individuals' civil, political, economic, social, and cultural rights from birth, and are stemmed from ideologies of dignity and autonomy. For this research, the following articles in the declaration are of particular significance: 1, 2, 3, 23, 25, 28, and 30 (See Appendix G). Some of these are elaborated here as exemplars.

Article 1 of The UNUDHR upholds the rights of persons with disabilities, in

stating that all human beings are born free and equal in dignity and rights. Article 2 specifies that this is not dependent on “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status” or the “political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.” Article 3 highlights that “everyone has the right to life, liberty, and security of person.” These Articles establishes that parents and children of medically complex needs have same rights as parents and children with no such needs.

The UNUDHR Article 23 (2) states that, “everyone, without any discrimination, has the right to equal pay for equal work.” However, in relation to my research, parents of children with medical complexities have dual roles as parents and caregivers, meaning they work as unpaid medical care providers. These unpaid caregivers are providing therapy, nursing, medical, and social work care 24 hours a day. Thus, the medical system in Ontario is taking advantage of parents’ free labour to fill gaps in funding and services that should otherwise be provided by the Ministry of Health and Long Term Care.

Further, Article 25, outlines that children with disabilities, and the caregivers of children with disabilities have a right to the same standard of living as everyone else: “everyone has the right to a standard of living adequate for the health and well-being of [themselves] and of [their] family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability ... or other lack of livelihood in circumstances beyond [their] control.” However, parent interviews unveiled how they and their children’s human

rights are constantly violated through CCACs withholding and limiting access to home care. One of the key ways caregivers and their children are discriminated against in the home care system is in how their needs are evaluated based on whether they deserve care compared to another child, rather than an evaluation based on their individual needs. All interviewed participants had difficulties in accessing timely and adequate home support care though their children met the definition of medically complex and fragile children as set by the Ministry of Health and Long Term Care. Inability to access timely home care supports resulted in social isolation, avoidable health disparities, and a lower standard of living for children and their parents.

In Canada, the Human Rights Act (1977) aims to protect individual rights to equal opportunity to make for themselves the lives they are able and wish to have. Individuals have the right to have their needs accommodated, in relation to their duties and obligations as citizens of Canada, without being penalized through discrimination based on disability (Human Rights Act, 1977). The Human Rights Act specifically states that people with disabilities have the right to equal opportunity to life and choices as non-disabled people. According to the Ontario Human Rights Code, everyone in Ontario has the right to live, work, and play with dignity, to contribute to society and have equal access to opportunities, without discrimination (Ontario Human Rights Commission, 2016). As with the Human Rights Act (1977), the Ontario Human Rights Code “prohibits actions that discriminate against people based on ... disability” among other protected grounds (Ontario Human Rights Commission, 2016). Inadequate access to home care supports is a violation of the Human Rights Act and the Ontario Human Rights Code, as

it can prevent children with medically complex needs from having equal access as non-disabled children to the community.

**Children's rights.** Children are afforded a distinct set of rights under the United Nations Convention on the Rights of the Child (CRC). The convention places emphasis on the dignity and equal rights of all children, regardless of background. That childhood warrants particular care and assistance means to provide necessary protection and safeguards (United Nations, 1989). And that children's rights are responsibilities that lie within the community. This research draws on 13 articles within the CRC as they pertain to child welfare and disability: 3, 4, 6, 9, 18, 23, 24, 41, and 42 (The United Nations, 1989) (see Appendix H). Some of these are unpacked here as exemplars.

Article 3 of the CRC specifies that the best interests of the child are the primary concern, whether public or private institutions take actions. Article 4 states children's rights to economic, social, and cultural rights must be upheld to the maximum extent of available resources. And Article 6 (2) upholds that children have a right to their "maximum" survival and development, and that it is the responsibility of States Parties to ensure this. Article 9 of the CRC supports in-home care when possible, as children are not to be separated from their parents against their will, except where necessary for the safety of the child, as in cases of abuse or neglect. Article 18 supports the raising of children by their parents, and that states and parties have an obligation to assist parents in their roles as caregivers through the development of "institutions, facilities, and services." These CRC Articles, affirm that parents and children with medically complex needs have rights to have quality home care supports.

Article 23 of the CRC pertains specifically to the care and rights of children with disabilities (1) State parties have an obligation towards children with disabilities to make sure they enjoy a full and decent life, particularly in relation to their dignity, promote self-reliance, and supports the child's active participation in community; (2) State parties recognize the right of the child with a disability to special care, and will encourage and ensure the extension, subject to resource availability, to the eligible child and the parents/guardians responsible for the child's care. The application for assistance is made in relation to the child's condition, their needs, and the circumstances of the parents or individuals caring for the child; (3) to provide services free of charge in relation to services developed to support the care needs of the child, and the child has effective access and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in relation to the child's abilities and to reach the maximum possible social inclusion and individual development – including their spiritual and cultural development- “whenever possible, taking into account the financial resources of the parents or others caring for the child.” Article 24 outlines the responsibility of the State to provide the “highest standard of health” through equal access to health care without prejudice. My research with parents revealed that the current state of Ontario's Home Care System violates the rights of children under the CRC. Although, CCAC has an obligation to assist parents in their caregiving roles, my research shows the contrary. Many parents reported spending years providing caregiving before being approved for home care, resulting in family breakdown and negatively impacting their development. These findings indicate that CCAC has not met their

obligation to protect children with medically complex needs from discrimination, nor has it ensured these children are provided with the supports to meet their maximum survival and development stages.

**United Nations Convention on Rights of Persons with Disabilities.** The Convention on Rights of Persons with Disabilities (UNCRPD) “imposes monitoring obligations on state parties exceeding those imposed by earlier human rights treaties” (Lawson & Priestley, 2015). The UNCRPD is an international legal document that reinforces the rights of persons with disabilities outlined in previous declarations, and clarifies those rights in particular situations, for example, the right for an individual with a disability to have access to health care that provides for an equal opportunity at life in Article 25 of the UNCRPD. For this research I focus on the following articles of the Declaration: 3, 7, 10, 17,19, 21,23, 25, and 32 (see Appendix I).

International human rights legislation not only focuses on specific rights, but also highlights five general human rights principles. These key principles are: “dignity; autonomy; participation, inclusion and accessibility; non-discrimination and equality; and respect for difference in relation to specific areas of people’s lives (i.e. social participation; health; education, work and privacy and family life, information & communications; access to justice; and income security and support services)” (United Nations, 2006).

Article 7 speaks directly to the rights of children with disabilities, first, that “States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with

other children”. Secondly, that the child’s best interest is the primary concern. Thirdly, children with disabilities have the right to express their views freely on matters pertaining to them, their views should be given the same weight as children without disabilities, and to be given “disability and age-appropriate assistance to realize that right.” This is further supported by Article 17, which states that all individuals with disabilities have the right to have their physical or mental integrity be respected on equal basis as other individuals. These Articles support that children and their parents as caregivers have the right to access homecare supports in order to have full “enjoyment of their human rights and fundamental freedoms,” and it is State responsibility to provide and monitor the services. However, interviews with parents showed how access to homecare was unnecessarily delayed, limited, and difficult to access.

Articles 19 and 25 speak specifically to accessing health care to support their full inclusion and participation in society. Article 19 states that access to “in-home, residential, and other community support services . . . support their living and inclusion in the community, and to prevent isolation or segregation from the community”. Article 25 outlines the right to access the same range, quality, and standard of “free or affordable health care and programs as provided to other persons,” including specific services that meet the needs of people with disabilities such as early identification, intervention as appropriate, and services which are designed to minimize further disabilities; that they are provided close to their communities; and they are not discriminated against in accessing health care and supports, food, and fluids based on their disability. Despite these Articles, my research confirms how the home care system in Ontario violates the

rights of parents and children with medically complex needs outlined in the CRPD.

Children with medically complex needs cannot have full enjoyment of their human rights and fundamental freedoms when their parents are suffering health issues and social isolation due to a lack of access to medically necessary supports.

**Canada Health Act, 1985.** The goal of the Canada Health Act (1985) was to establish the responsibilities of provincial governments to meet specific criteria and conditions that ensure the provision of specific health and extended health care services and provide for the requirements to access federal funding for health care. The Act asserts that it is the responsibility of provinces to develop health services, and therefore, each province creates their own specific health services. However, the Act has some specific requirements that must be met: the public administration of health insurance, that health care is comprehensive and all individuals must be covered for medically necessary health services, the principle of universality, that all residents must be covered by the insurance plan on uniform terms and conditions, portability, that all individuals must be covered by insured health services wherever they access health care in Canada, and accessibility, everyone must have access to insured health services without discrimination, without direct or indirect financial charges, age, or health status.

Furthermore, provinces are required to offer specified health services (i.e. home care service) and extended health care services before federal funding is released. In my view, the requirement of 'being already in place' for homecare support services does not translate to equitable access. Home care services are not considered 'essential service,' rather they are 'extended services' under this act, resulting in different variations of home

care services across provinces, where the same population have different access to home care services. Therefore, this law seems to fail to protect the notion of equity in relation to access to health care.

**Home Care and Community Services Act (1994).** The Home Care and Community Services Act (1994) (HCCSA) (See Appendix K) is designed to specifically prevent discrimination in accessing health care based on disability. The HCCSA outlines that options for community care should exist where possible, that supports for caregiver respite are available, that quality services that prioritize clients needs and preferences are available, that services are coordinated to provide a continuum of care, that there is equitable access through consistent and uniform eligibility criteria, and that there is cooperation and coordination of services in the interest of the client. The Human Rights Code (see Appendix J) and the HCCSA are significant to my research as they clearly show the rights to specific home care support for both parents and their children with medically complex needs in Ontario. Under the HCCSA (1994), the bill of rights (see Appendix K) upholds patients' right to be treated with respect, free from abuse, in a way that respects their inherent dignity, autonomy and right to privacy, including their right to free and informed consent and their right to participate in decisions regarding their treatment. These provider responsibilities were specifically examined in the qualitative interviews conducted with the unpaid caregivers in relation to their Personal Support Workers (PSW) and nursing services for homecare supports.

This review of human right laws and conventions reveals an emphasis on caregiver and children's rights to equitable home care support (answering questions 1-2

listed on page 11). The reviewed human rights laws and conventions will be discussed further in Chapter 4 in relation to findings from my qualitative interviews, along with social mechanisms that allow for such rights to be violated.

### **Part B - Interview Findings**

I am applying an intersectionality framework and an intracategorical approach to interpret interview findings. The intracategorical complexity approach constructs social identities as boundary masking and having a boundary defining process. There is an acknowledgment of the stable and consistent relationship that social categories represented in society at any particular moment in time, and a critical approach towards categories and identities within society. Intracategorical reference a focus on how specific social groups/communities are neglected at points of intersection. The following are thematically based interview findings described through participant narratives and my interpretations as the researcher.

**Characteristics of participants and their children.** Before I begin to go through the findings I want to provide a detailed description of the 12 children with medically complex needs whose parents participated in my study. Ten of the children are unable to bear weight, stand, sit, or walk. Eight of the children had visual impairments. Nine had seizure disorders that require 24 hour/day monitoring, daily medication plus rescue seizure medication on a daily basis, and in some cases, several times a day. Eleven of the children required full repositioning. Ten used manual wheelchairs/paediatric strollers. Many of them feed through a G-tube, and two feed orally with someone feeding them. Nine did not have use of their hands. One child had extreme behaviours and severe

aggression to the point of self-harm and harm towards others. One child could walk with the assistance of a walker, and one child could walk on their own. All these children require full time care in all aspects of their life, including their eating, sleeping, repositioning, transfers, toileting, as well as constant supervision 24 hours a day, as well as daily medical interventions. These children are part of one of Ontario's most marginalized populations.

The parents all spoke English, all were women and the primary caregivers in the family. Three out of the 10 participants were single mothers, and the other 7 were married with supportive husbands. Three of the participants were living under the poverty line and the other 7 participants had middle-class family incomes. I have replaced actual names of the participants with pseudonyms.

**Finding 1: Impact on health.** An important finding was the health implications for families when there is little to no access to home care supports for their children with medically complex needs. Nine of the 10 participants had negative experiences accessing home care supports for their children, they expressed that their first priority was keeping their children alive, then advocating for home care supports, and their own health suffered because of this. Nearly all participants spoke of physical health issues, mental health issues, and a lack of social well-being due to lack of access to home care supports to support their continual care of their children. One participant, Sarah described what it was like to have sleep deprivation and lack social well-being:

*Well—my son was 24 hour care . . . I have no family, no friends, so basically I was sleep deprived for 8 years . . . and I did not have services. I was lucky to sleep 2*

*hours a night, and not even continuous and together . . . because I was . . . lifting him and caring for him all by myself . . . I've destroyed muscles in my back . . . and hands . . . add to that my anxiety, depression, and continuous stress, and my ex-husband who was also very depressed . . . and he became abusive, and eventually we separated.*

Further, she expressed how she felt disregarded, bullied, and demoralized by CCAC:

*I felt like I was begging for favours. . . they looked at me like I was garbage . . . constantly telling me that other parents in the community were doing better than me . . . it was demoralizing me . . . and also demotivating me . . . taking my strength away as a person and it was crushing my spirit. (Sarah)*

Families felt powerless and felt like they were begging for a service that was essential for their survival and the survival of their child. Emile stated,

*“So my children have changed. They're heavier, they're bigger. I mean, they're going on 16 and my youngest son just turned 14 and with them still having complication following surgery. . . . I just went through a screening process on Monday, and now the boys have gone down from . . . 40 hours a week . . . between both of them, to 7 now. . . . I'm entitled to seven hours of PSW for each boy at this point in time.”*

Service providers such as CCAC case coordinators and CCAC managers were actively contributing to the demoralization of parents diminishing their overall health, social well-being, and mental health. Central to this finding are the dual identities of being a caregiver and parent. The lack of acknowledgement by professionals regarding

the work they were doing as caregivers, coupled with accusations regarding their ability to take care of their own children made them feel shameful for asking for help. Some reported feeling as though “*they were a bad parent*” (Sarah), for asking about home care supports for their children with medically complex needs. They ought to feel “*grateful their children were not as bad as others*” (Sarah) medically speaking. Parents were made to feel as though what they were asking for was excessive in relation to others in similar or worse situations. When service providers used this tactic of comparing families it created unequal power dynamics between service providers and families, and diminished the dignity of families of children with medically complex needs.

These parents’ responsibility for the extensive care of their children in order to keep them alive caused anxiety and constant worries that contributed to family break down. Erica said,

*You know what, I think that they think that just because we're parents that we do have to take care of our kids, but our kids are different than just taking care of a normal child, because, you know what, the rest of the family suffers. The rest of them . . . like, the other two suffer, unfortunately, because Matthew comes first. . . You're more in a caregiver role right now than you are as a parent. . . Like, I find that I'm trying to keep him alive more than I am as a parent that, you know what, oh, let's go do this or let's go do thi. . . but health and everything else like that, and his fragility is ... kind of hinders it. So it turns your life around, I find.*

Many of the participants did not have access to home care services until their children were at least eight years old, with a few cases not until over the age of 13, even

though eight of the caregivers reported their children with medically complex needs could not sit, walk, or hold their head up, requiring full caregiving in all areas of life. Their children could not feed themselves, play with others, and they missed a lot of school due to hospitalizations or illness. Further, nine out of 10 participants had children who were dependent on medical technology. Lisa described how her first priority was being a caregiver, *“I live 24 hours as a caregiver first and then if I have time in-between I become a parent, but my job is to keep my son alive is my priority.”* Of note, the participants in my study were all women and they were the primary caregivers to their children with complex needs; a finding consistent with others reporting women’s disproportionate responsibility for unpaid caregiving in society (Morris, 2004). Seven of the participants were married to men, and three were single parents. Of the eight who were married, their spouses were involved in the care of their children, however the women were the primary caregivers.

The interviews revealed the negative impact that the intersecting identities of being a parent and essentially a medical caregiver had on participants’ health and caused family breakdown, when they lacked access to home care supports. This can be attributed to their identities as parents being taken for granted, and the 24-hour care they had to, and were expected to provide. These caregivers were doing the work of medical professionals, but not being afforded the same respect or financial compensation as medical professionals. Access to services continues to be an issue of equitable to access because CCAC withhold home care supports from a population who has the right to access them, while staff at CCAC are aware of the health implications, family

breakdown, and strains it causes. Further, it is an equity issue because the increased stress in the home impacts children's ability to thrive.

**Finding 2: Breach of trust.** Existing literature reports that trust is important element in creating partnerships with parents and service providers (Musa et al., 2009; Whetten et al., 2006). Trust requires a relationship of mutual respect and honesty developed over time. In the interviews I conducted, many of the unpaid parent-caregivers spoke about the revolving door of case coordinators resulting in a lack of consistency and reliability. Children with medically complex needs require consistent case coordinators who know their case and when someone new is on the case it creates anxiety and frustration because families have to relay information again, get to know someone new, and build trusting relationships again while caregiving their child, "*this woman's only been with my family for four months... She'll be gone June*" said Elisa. Participants reported that they developed a distrust of CCAC because workers have treated them disrespectfully, provided false information in order to deny proper care, and discouraged them from advocating for home care services.

Eight participants felt that CCAC staff, specifically, case coordinators and managers, belittled them as parents and made them feel bad for asking about home care supports for their children. They felt exhausted and like "*everything is a battle with CCAC*" (Elisa). Participants generally felt a huge power discrepancy between themselves and CCAC as they were in constant fear of losing their services. Home assessments felt unsafe because of comments the coordinator would make, and the power they had to take away services. As Sarah recalled what a coordinator had said to her, *you're not doing a*

*good enough job because you're asking for help . . . that means you're not a good parent."* Another participant stated,

*So initially very, um, it was very challenging to access additional hours . . . when I would ask for more hours, I would be lucky if I would get another one or two hours a week. And, just to put in perspective, I was getting maybe 6 hours initially, and for a son that is completely, um, like he's severely disabled, and could not do ANYTHING HIMSELF – still cannot. So he needs full care. (Neveah)*

Once parents realized their children were eligible for services throughout the entire time they were advocating and asking for more information – the trust between CCAC and the parents was broken. Sarah said,

*I was shocked to know that I was eligible for services all these years, but I was denied them, and as a result, it costed me my marriage, it costed me my mental and physical health, it costed me so many things, uh, I would never forgive them for that . . . well they said my son is not enough complex, that services are given only to people who have oxygen, uh and that there isn't enough money from the government, from the Ministry, so uh there isn't enough hours, there isn't enough funding and they only -- only people who have oxygen and ventilator and trach are the one who are eligible for help and for any kind of services, even though . . . my son is very complex. He is in the complex care team in Sick Kids, uh, he has a G tube, he needs suctioning, he has an oxygen monitoring machine, um he's constantly sick, he's admitted to hospital many times, he has daily medical appointments, uh, I mean his special needs is a long, long list and to be able to*

*get into the complex care in Sick Kids, you really have to be complex to be able to get there.*

Participants were not given information about what services existed, eligibility criteria, mechanisms for appeal, which are all essential information for families to be able to advocate for services. Additionally, there were inconsistencies in what the families were told by CCAC. Nine of the caregivers said there were discrepancies between what services CCAC would tell them were available and what they heard from other parents. Joan said, *“So families are getting told very different messages depending on who their CCAC manager is and that’s just not right.”* Parents supported each other by sharing information in order to navigate Ontario’s home care system. Julia, *“To be honest, it was more parents that were more helpful than actual service providers. I found that I was fighting even just to get information about the different programs that are available, let alone the eligibility.”*

Julia stated *“I feel like there should be more information that’s accessible and available to people.”* Seven of 10 of the participants were not aware of the different appeal mechanisms and who to contact for extra support. Families spent an extraordinary amount of time researching laws and trying to find policy manuals online to educate themselves in order to learn how to access home care supports while caregiving their children with medically complex needs, enduring severe exhaustion, and family breakdown. In my view, in order for parents to be successful in their dual roles as parents and caregivers our system needs to provide correct information, access to clearly written policy manuals, and information on appeal systems.

Many of the participants had revoked consent to share information between leading paediatric facilities, physicians, and their CCAC because of this broken trust. Seven of 10 participants had revoked consent between the CCAC and all medical professionals and medical facilities, including The Hospital for Sick Children, and physicians in a strategic move to protect their children from losing home care supports. Zara said,

*So, based on what other parents told me to do, the only way I could get any further was to pull consent away from CCAC and then they finally took me seriously. Then they changed care coordinators, although they, they said they shouldn't because this is our only children's coordinator.*

Parents specifically noted that CCAC workers would minimize their children's conditions to health care professionals to justify reducing or denying services. Sarah said,

*I was suffering from major PTSD . . . with the same stress I expressed to the hospital and the same stress expressed to the paediatrician, the paediatrician had a solution for it . . . and he said there's CCAC in the community, they can come out and help, write your supporting documentation, you need to be very vocal and you need to stand up and ask for help when you need it. . . . It was pretty much predetermined in their [CCAC] minds . . . how much can she question us, how much can she push us, that's what it felt to me. . . . because everything was laid out, nothing was changed. My son's condition didn't get changed, it only got worse. My personal life didn't get better, it only got worse, so I don't think it was misunderstanding or the way I was explaining it to them, I think it was just a*

*matter of what can we do to shut her up. And when I would not shut up then they had to go back and forth to the point the [fittest wins], but basically that's it.*

Parents noted that CCAC workers would hold conversations, with health care professionals and leading paediatric institutions, about the children without their consent, or with very little notice, as a way to exclude them. However, it is important to note that generally, parents felt their physicians and hospitals were supportive of them receiving home care supports.

When applying intersectionality through the lens of power to this finding, there is an apparent power imbalance between parents and the CCAC staff. The most pressing finding was the way in which all the participants were primary caregivers and were women. The intersection of being an unpaid caregiver and a woman situated these parents as having a marginal identity in the context of Ontario's Home Care System. Within our neoliberal society, we situate women's bodies within margins of caring roles and socially construct their identities throughout this process (Armstrong & Armstrong, 2004; Marika Morris, 2004). An added layer of complexity was the socio-economic status of families. For example, families who were middle class and educated were able to educate themselves about what policies existed, while individuals living below the poverty line did not have the same ability to navigate policies as easily due to their socioeconomic status and their education abilities. Furthermore, participants reported that their dual roles as caregivers and parents were used by CCAC staff as a means to silence them and prevent them from advocating for home care supports.

**Finding 3: Financial implications.** Employment and unemployment for the unpaid caregivers of children with medically complex needs varied and the contributing factors were access to home care supports, and accommodating employers. Six of the 10 participants worked full-time hours when they had home care supports in place and accommodating employers. For example, Neveah shared,

*Well, I'm so lucky that I have the same employer for seven years. . . . It has been recently, where, um, you know I had to take a leave of absence . . . but my employers has been very understanding and they understand the situation, and I do get to work from home.*

While the remaining four participants could not work because they didn't have accommodating employers to begin with, they lacked adequate home care supports, or they felt the needs of their child were too high and they would not find employers who would be accommodating.

*That is why I don't work cause my son is 24-hour care- and well, I am working with him 24 hour . . . but there is no way I can afford any kind of work outside, there is absolutely no time to even deal with my son's needs, forget about anything other than that... it means that my dreams, I had to forget about them. I'm an electrical engineer by education, and I am not able to use that at all in anyway with my son. (Sarah)*

Another participant, Chloe noted, not only does her son suffer from a severe seizure disorder but he also has insomnia,

*I had to quit work in 2014 because of no sleep. I manage. I'm in university now, I managed to work my school schedule around his schedule, but once I'm done school I don't know if I'll ever be able to go back to work with this type of sleep schedule. We can't make any plans.*

It became apparent even with accommodating employers there was a gap in health benefits as families would have to give up vacation days to attend to their children's needs and their appointments. Some of the families noted having to work through their lunch breaks to make up time missed so they could still use their vacation days for vacations. Zara, another unpaid caregiver said,

*My husband does all of the appointments right now, because I just can't take that much time off. And any time I do take time off, I have to make up for it? So, I'm usually like giving up my lunch hours to make up time that I've missed for appointments. Because I don't want to use my vacation time, cause I kind of want to use my vacation time as vacation, not for appointments.*

This is an important finding because being out of the home to work without ability to maintain employment mean they are not being properly supported in the workplace nor have adequate home care supports. Neveah stated,

*I felt like it was only when things got really bad, and that we beg and things were so bad I couldn't work, that you know we were able to get support . . . maybe all of this could have been avoided if we would have been given help in the beginning.*

Furthermore, there was a positive association between having adequate home care supports and having employer accommodations to be able to work and care for their children with medically complex needs. Joan Shared,

*Yeah, well, I asked for more hours, I also adjusted what we were asking for. I wanted to go back to work a bit two years ago, so I asked for more hours and . . . they said, “We can give you more hours but we’ll go from RN to RPN,” and I agreed.*

From the perspective of an intersectional lens the dual identities of being both parents and caregivers, highlights the power discrepancies between employees and employers. The unpaid caregivers reported that they have to negotiate their unpaid work as caregivers and their paid work as employees, which often results in their marginalization. Participants’ financial resources are impacted, according to the participants by the high number of days they have to be absent from work, and the need for employer accommodations impacts their employment security. Their identities as caregivers places them in the margins of oppression as it impacts their access to employment and financial security, first by decreasing their ability to work; and second by increasing the accommodations they require when employed, if they are able to find accommodating employers. It is important to be careful not to assume that all parents of children with medically complex needs can work, have access to accommodating employers or can be self employed, as in the case of one participant.

Financial barriers associated with the inability to access home care supports is one of many key findings. Some of the participants were middle-class while the remaining

were living below the poverty line. However, all the families' decisions on where to live were influenced by having to pay for some level of support before receiving adequate home care through the Ministry. For example, Neveah explained,

*you know maybe because we live in a, you know a house with a double-car garage and you know it looks like we have money, but its like- I mean is very deceptive... the amount of care and services that we- my husband and I have to pay out of pocket- has put us in a situation we're literally in debt every month and couldn't afford it... eventually we had to sell our house and now we lease.*

Emile was told they needed to renovate their house before home care supports could come into their home but they did not have the financial means and there was no outside funding available for them. Emile claimed that it became evident later that this was an excuse to deny services as the family was able to obtain home care supports without having home renovations. Samantha had the same experience, *“If you don't do the home renovations you can't have nurses anymore. But they wouldn't give us any money for the home renovation, that was hard. That they're doing me a favour, I need help, I don't need favours.”* Samantha felt that the CCAC treats parents as if they should be expected to be unpaid caregivers around the clock, *“I think their expectation is that I am both and they are willing to throw me a bone to help a little bit sometimes, but it's my responsibility to be both, all the time.”*

#### **Finding 4: Listen to Us and Talk to Us When Creating Policies**

Each participant was asked to provide policy recommendations (see Appendix L for a full list) and the common finding was the importance of engaging parents in order to

bring their perspectives to the Ministry of Health & Long Term Care, CCACs', and LHINs.'

*So if the policymakers are writing policies, I highly recommend involving parents [as] part of the policy writing process, and even when they're doing research. . . . Also taking feedback from parents, from caregivers, and feedback from physicians who see their patients most . . . the Ministry of Health and Long Term Care should ask me directly, to me what your child needs, tell me as a caregiver what we can do to support you to make you more enabled. (Sarah)*

Additionally, many of the participants spoke about how they wished CCAC case coordinators, managers, and directors, and the Ministry of Health & Long Term care would come spend a day with them to see what their lives were like before creating policies. Julia said,

*Maybe if they got to see her a bit better and see what our day to day life actually is instead of having, like, a two-hour meeting and seeing her for 40 minutes and then making a decision based on that and based on medical documents that don't actually explain who she is as a child and who we are as a family. It seemed like a really cold process to me. . . . there was no trying to understand who we were and how we function.*

I argue these interviews illustrate the way in which the Ministry of Health & Long Term Care needs to include unpaid caregivers throughout the policy process, and continue to seek their input even after policies are created. Marginalization and oppression occur when the lived experiences of the targeted population are excluded from policy-making

process. Parents need to speak up against the social injustices they have faced within Ontario's Home Care System. As Jennifer Nash (2008) wrote,

“Crenshaw's intervention (of using intersectionality) suggests the importance of ‘speak[ing] against internal exclusions and marginalizations’ to challenge institutions and radical political projects to hear the voices that have been silenced. Now that intersectionality itself has become an institutionalized intellectual project, and the dominant tool for excavating the voices of the marginalized, it is incumbent upon intersectional scholars to critically interrogate the goals of the intersectional project as they determine how to chart the future of this theoretical and political movement” (p. 89).

In my view, if the Ministry of Health & Long Term Care, CCACs, and LHINs are sincere in having equity as part of their mandate, they need to build partnerships, engage parents, and begin listening to the community to address the inequities they face.

#### **Chapter 4 - Discussion**

The intent of this study was to examine the experiences of parents as unpaid caregivers accessing home care supports for their children with medically complex needs in Ontario. The present study makes a contribution to literature in this area, highlighting the barriers and subsequent implications these parents as unpaid caregivers and their families face when trying to access home care supports. My findings were not developed in a vacuum, with the use of intersectionality theory I identified how participant identities and experiences are shaped by their particular social, economic, cultural, and political

locations, and how existing social processes allow for their continued marginalization and health inequities.

Applying a human rights framework to the participant experiences with the health care system, I have identified how the rights of unpaid parent-caregivers and their children are being violated when accessing home care supports. Rights' violations included the right to equal opportunities at life, and the right to prohibit discrimination and discrimination by association (one cannot be discriminate against due your association, relationship, or interactions with another person – for instance, an individual is not permitted to participate in an a school event because they have a disability, or an individual is denied home care services because they are an immigrant family) as stipulated in the Ontario Human Rights Code (1990) and the Ontario Home Care & Community Services Act (1994). I have identified four key findings relating to accessing home care supports for the parents as unpaid caregivers of children with medically complex needs in Ontario.

The three key findings are: (1) The impact on caregiver health as a consequence of inadequate home care supports (2) Breaches of trust when service providers withheld and/or provided inaccurate information about available services; and (3) Financial implications from inadequate home care supports. The first three findings based on the first-hand experiences of the parent-caregivers are discussed here as they reveal violations of Ontario's Human Rights Code & Ontario's Home Care & Community Services Act.

### **Ontario Right's Violations**

The CCAC workers are obligated to communicate and act with their clients in accordance with the bill of rights outlined in the Home Care & Community Services Act (1994) (HCCSA) (See Appendix K). There are nine subsections within Section 3 of HCCSA; through my research I found that every single one was being violated and had negative implications on participants and their families, health, social well-being, and family cohesion.

The rights of parents and their children with medically complex needs in the bill of rights are: (1) the right to be treated with courtesy and respect, and not endure any level of physical, mental or financial abuse by service providers when retaining home care services; (2) their autonomy, dignity, and privacy must be respected; (3) the right to be dealt with in such a way that their individuality is recognized, and their needs and preferences, including ethnic, spiritual, linguistic, familial, and cultural factors are respected; (4) the right to be provided with information about the community services and to be told who will be providing such services; (5) the right to participate in the service provider's assessment, development of the plan of service, and evaluation and revision of the plan of service; (6) the right to revoke or refuse consent to any service provider; (7) the right to raise concerns or recommend changes in relation to community service provided to them (and also in relation to policies or decisions that may impact their best interest) without fear of interference, coercion, discrimination or reprisal; (8) the right to know what laws, rules and policies affect the operation of the service provider,

and to be provided in writing how to initiate complaints about service providers; and (9) the right to have their records kept confidential in relation to the law.

### **Finding 1: Impacts on health**

Participants spoke of a lack of meaningful home care supports and how a last-resort approach to eligibility resulted in their own physical and mental health issues, as well as family breakdown. Many of the participants did not have access to home care until their children were eight years old, and some not until their children were thirteen years of age or over. Nine out of 10 participants suffered mental and physical health issues due to the increased amount of caregiving they had to do for their children when they were denied access to adequate supports. The priority of these parents was to keep their children alive, and having to advocate for home care supports increased their workload.

Participants spoke of constant demoralization, impacting their social well-being and mental health. The CCAC workers made them feel as though they were 'bad parents' asking for nonessential help. Participants described being compared to other families who were characterized by the CCAC as having children with more complex needs than their child. The CCAC were described as not acknowledging the labour intensity of their caregiving role and the health consequences, such as body aches, severe sleep deprivation, PTSD, depression, and anxiety, they suffered. Under the HCCSA (1990) section 3 (1-3), this is a violation of parent caregivers' right to be treated with respect and courtesy, autonomy, dignity, and privacy, and their right to have their individuality, specifically familial factors, recognized. Additionally they were entitled to access such

services under the HCCSA, and not be to be discriminated against by association as outlined in the Ontario Human Rights Code (OHRC) (1994), sections 12 and 17(1). The denial of services for their children with medical complex needs, a protected class of people in the OHRC, created unnecessary health consequences to unpaid parent-caregivers.

My data suggests that CCAC's approach to the provision of home care support is currently reactive resulting in negative consequences to the health of parents as unpaid caregivers. The reactive approach violates parent-caregivers' right to dignity and autonomy because in order to receive health supports for their children they have to be almost or completely burnt out, for example, suffering from sleep deprivation, physical and mental health issues, family breakdown, and financial hardships. This approach violates not only HCCSA, 1994 but also the premise of Ontario's Human Rights code that all humans should have equal opportunity in relation to enjoyment of life, family, health, education, employment, etc. Also, their individuality as parents and caregivers are not respected when supports are only available as a last resort. Additionally, in my research findings and from my personal perspective, the entire approach to home care services has not been supportive and is leading to rights' violations and ongoing marginalization.

### **Finding 2: Breach of Trust**

Trust between the CCAC service providers and parents was broken as parent-caregivers felt that service providers withheld information and/or provided inaccurate information about available services. Such lack of trust was expressed by eight of ten

participants who spoke of being disrespected, and receiving false or incomplete information from CCAC workers, such as minimizing the maximum legislated amounts available to parents for home care supports or conveying to most of the parents that their children were not eligible for services. Participants identified this as a reason for being denied proper home care supports and feeling discouraged to even advocate for homecare supports. As I applied the human rights frameworks, this finding, violates section 3, subsections 2, 5, 8, and 9 of the HCCSA. The section 3 (2) explicitly states that people have the right to be treated with respect, autonomy, and have their privacy respected. Section 3 (5) stipulates that people have the right to participate in their assessment, plan of service, and evaluation, none of which could happen when parent-caregivers were being provided with false information. Seven out of the ten participants were not aware of the different forms of appeal (internal vs. external) within Ontario's Home Care System. This finding is in direct violation of subsections (4), (5), and (8) of the bill of rights under the HCCSA. It seems that the CCAC took away parents' ability to meaningfully participate in the service provision process by providing inaccurate and incomplete information. The section 3 (8) clearly states that the CCAC has a legal obligation to inform clients of the policies and legislation they operate under; withholding of such information implies a denial of parent-caregiver's right to know what information was accurate and what supports existed. Thus, the right to information was reported to be violated on numerous occasions.

The lack of trust among parent-caregivers also led seven out of ten participant parents to revoke their consent with respect to information sharing between the CCAC

and their medical professionals. Parents revoked consent because (1) CCAC held conversations with these medical professionals without their consent, or with little notice to be able to participate in these discussions, and/or (2) parents worried that CCAC would use these conversations as a means to justify reducing or denying home care services. Not treating parent-caregivers with courtesy and respect by not asking for consent or providing enough time to make informed decisions about consent to share information is a violation of the HCCSA section 3 (1). This also violated their right to autonomy, section 3 (2). Denial of their ability to exercise informed consent also included not being informed of their rights under the HCCSA; section 3(8) clearly states that individuals accessing home care supports have the right to know what laws, rules, and policies affect the operation of their service provider, in effect, they have the right to know about the bill of rights.

The findings suggest that the parent-caregiver's right to have their records kept confidential was violated. Unpaid caregivers' right to confidentiality includes that caregivers provide informed consent for health care services to share their information. Some parents chose to revoke consent between CCAC and health care professionals and medical institutions after their right to information and confidentiality were broken. I argue that this was a strategic move to protect their children from losing home care supports. Participants expressed the importance of physician's and other health care professional's support for accessing home care, in this context it is important to understand how parent-caregivers' revocation of consent is a political tool they leveraged and the oppression families face when they decide to revoke consent.

Parents experienced multiple forms of oppression and right violations that led to their decision to revoke consent. They were subjected to socioeconomic discrimination as their position as both parents and unpaid caregivers was used to ignore their expertise as caregivers. Participant parent-caregivers discussed that the CCAC workers withheld information as a delay tactic to deny home care supports and this pushed participants to spend their time trying to access the right information. The CCAC workers seems to have mishandled the health information, in violation of law, by sharing information with paediatric facilities without consent, and scheduled meetings with health care providers without adequate notice denying parents the opportunity to attend. Control over who has access to their children's health information is one of the few powers that parents seemed to have in their fragile situations.

Participants expressed how the CCAC workers used health information in whichever way they chose even when it resulted in their further exclusion, oppression and marginalization. In this way giving consent to the CCAC was experienced by participants as detrimental and families revoked consent to take power back. Thus, consent became a political tool for families to change how home care was delivered - through forcing the CCACs and health care professionals to collaborate. By choosing what information was to be shared and deciding who could participate in conversations they became gateways to redefine the parameters of home care.

### **Finding 3: Financial Implications**

Although seven out of then 10 participants were employed, their employment was dependent on receiving home care supports and finding accommodating employers,

ultimately resulting in financial strain. Some had to use their lunch breaks to make up for absent days to attend their children's needs while one was self-employed, and the remaining participants were unemployed and living below the poverty line. Parents felt that the CCAC staff intentionally down played their roles as caregivers, contributing to their financial burden through denial of provincially funded services for home care. Specifically, CCAC case coordinators were described by some as ignoring how home care support services are necessary for families to access employment. The provision of home care services open doors for employment, when they are denied parent-caregivers become vulnerable to unemployment. Applying human rights' framework, there is violation of subsections (1), (2), and (3) through the *bill of rights* under *HCCSA*.

Subsection 2 of the bill of rights explicitly states that families' and their children's dignity, autonomy, and privacy are to be respected. Participants had little to no home care supports despite meeting the eligibility criteria. How can their dignity and autonomy be respected when they are expected to work outside the home while providing care 24 hours a day seven days a week? This finding reveals how the right to work within the employment sector, what employment status participants have, and how their dignity and autonomy are controlled through access to home care supports.

### **Summary of Findings**

Overall, the interview findings revealed that home care services for children with medically complex needs are provided by CCACs as a last resort, after informal supports are exhausted, and often result in burn out, mental, emotional, and physical health problems, family breakdown, and economic hardship. All the participants shared they

needed increased supports for their children with medically complex needs. Additionally, they highlighted how their children's quality of life is directly affected by what supports they receive and how those supports are accessed. Participants emphasized that their children are valuable human beings who *“deserve their needs to be met . . . and I think they give a lot back to society . . . they're extremely valuable human beings”* (Joan). As service providers continued to decrease home care services in relation to the increasing age of a child, parents questioned why service providers, who are supposed to ensure equity among these marginalized citizens, instead continue their marginalization?

Through applying human rights frameworks, I unveil how CCACs seemed to have perpetrated systemic violence on children with medically complex needs and their unpaid parent-caregivers. The CCACs continually violated the rights of the unpaid parent-caregivers and their children with medical complex needs through dehumanizing practises contrary to the foundations of rights, creating situations where children with medically complex needs were not provided with the same quality of life as children without medically complex needs. It is important to note how their rights as children, as individuals with disabilities, and as human beings were constantly violated, and the implications (i.e. social isolation, social well-being, employment, family breakdown, and health) for them and their parents. Despite being given proper documentation by leading paediatric facilities and health care professionals supporting these families' needs for home care supports, the CCACs were described as consistently denying adequate service. The CCACs and health care professionals have access to an extensive body of research on the importance of home care supports for children with medically complex needs, yet

power imbalances were regularly used as a tool to deny necessary health care. Given that in most cases the barriers participants and their children experienced, were rights violations - rights established in Ontario's Home Care & Community Services Act, Human Rights, Disability Rights, and Children rights – often perpetrated by the CCACs, urgent action is needed by governing structures and community advocates. Using an intersectional lens, it became apparent that a reactive approach to health care delivery and funding has resulted in the marginalization of these parents. Participants had to experience health issues, lack of social well-being, and social isolation before they were able to access home care for their children. CCAC workers are quite aware of how unpaid caregivers are pushed into precarious positions of caring, playing into the discourse of parental responsibility and withholding formal supports as a last resort. Parents reported that they want formal supports before their families' breakdown and they argue that the government has a fiduciary obligation, based on human right laws and conventions, to provide this support. They all emphasized the need to bridge parent-caregiver, community service providers for home care support, and government bodies for meaningful solutions.

### **Authenticity: Implications for Policy, Practise, Research, and Engagement**

The engagement of the community of parents of children with medically complex needs in Ontario was instrumental in developing the questions and design for my research. The parents explained what they wanted to share with other families, to reduce isolation; and what they wanted those in positions of power (policy makers, decision-makers, health professionals) to know. Similarly, the development of policy needs to

occur with the engagement of the communities they are being developed for; there is inherent value to interacting with the individuals with lived experience in order to inform policy to understand implications.

There are many benefits to engaging community in research and policy. An important tenet in community engagement in policy development is valuing marginalized peoples as experts of their world and the oppressions they experience (Woolf et al., 2016). Engaging parents of children with medically complex needs by spending a day with them to understand what their lives are like on a daily basis, when creating policies and for MOHLTC, LHINs, and CCACs can be a way to inform policy, practice, research, and community engagement. Although engagement is time consuming, it aids in formulating trusting relationships, and leads to developing policies in the best interests of those who are meant to benefit from them. In creating partnerships with the stakeholders (and/or participants) it is important to note the sense of ownership over the policy process, which occurs through the authentic engagement between the various actors. Authentic engagement promotes agency and empowerment, an especially important outcome as current processes result in their continuous marginalization and oppression. Finally, in my view, there is inherent value in witnessing the lives of marginalized communities in order to understand and inform the policy process. If they did witness these parents' lives, policy decision makers would understand that they want to be parents first and caregivers second. However, their children's complex needs and inadequate home care, means they take on many roles and they rarely get to be parents. Zara stated,

*We had children to be mothers, not to be speech and language pathologists, not to be PTs, OTs, PSWs, DSWs, RNs, RNAs. We should be a mum. We should have the mother role, not those other roles that just, kind of, consume our lives because of no funding or not finding reliable people to help. That's a big issue. People that truly, genuinely show empathy and compassion towards our kids.*

### **Study Limitations**

The findings presented in this paper are limited in their generalizability because the research is based on a small sample of the parent-caregivers of children with medically complex conditions. All participants were residents of Ontario and most of them were employed. Further research could include a larger sample of parents not engaged in paid employment. With regard to employment and health impacts, more research needs to investigate what it means to work when people have children with medical complexities, what adequate work accommodations would look like for this population, and within Ontario, how different ministerial governments (i.e. Ministry of Health, Ministry of Labour, Ministry of Community & Social Services and, Ministry of Economic Development and Growth) can support this group of parents to maintain employment outside the home. Further, I did not collect data on race, nor have a large enough sample to draw any conclusions on how race may or may not intersect with access to home care supports in Ontario. Access to health care has been linked to race, for example, Indigenous populations do not receive the same access to health care as non-indigenous Canadians (Smylie & Firestone, 2016). Additionally, without information from a third party or access to their health care files, there could be bias in participants'

reports of how much care or underrepresentation of the care they were provided. A mixed-method approach with this population could be used in future research to provide more insight into the experience of accessing home care supports for this population group.

### **Conclusion**

This research unveiled the barriers unpaid parent-caregivers face trying to access home care supports for their children with medically complex needs in Ontario. There were severe implications due to inadequate home care supports including: family breakdown, barriers to employment, financial hardship, and health inequities. The dual identity of unpaid caregiver and parent was not respected, and in some cases, misunderstood. Navigating the home care system for supports for their children was very difficult for nine out of the ten participants in this research and resulted in the violation of their fundamental rights according to provincial, national and international Law. Collectively, participants explained the importance of trust in their relationships with the CCAC. CCAC workers need to develop trusting and respectful relationships with clients so that families can share their experiences of what it is like to raise a child with medical complexities without home care supports, and continue to receive support for their children and families through Ontario's home care system.

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## Appendix A

### Verbal Informed Consent

“Hello All,

I, Samadhi Mora Severino, am a student in Master of Arts program in the Department of Critical Disability Studies, York University in Toronto. I am conducting research on the inequities of accessing home care supports for children with medically complex needs children in Ontario. I am approaching you as a potential participant in this research. The proposal of this research has been reviewed and approved by the Ethics Review Committee of [Critical Disability Studies Graduate Program](#) and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

**Aim and Procedures:** I would like to gather perspectives of parents/guardians about their experiences of accessing homecare supports for a child with medically complex needs. For this purpose, a willing parent/guardian will be invited to participate voluntarily in a semi-structured interview offered as one-to-one or in a group format; the expected duration is 60-90 minutes. The interviews will be recorded and transcribed. Participants will be able to withdraw from the study at any time without penalty as it is their right. You will be offered a review of interview transcripts, if your desire so.

**Confidentiality:** All information provided by a participant during the research will be held in confidence and no name will appear in any report or publication of the research, unless a participant gives permission to disclose his/her name on the consent form. *I will collect the data from hand written notes and digital recordings of the interview.* The audio taped interviews will be transcribed word-to-word and any names mentioned in the interviews will be removed. The audio files will be deleted after transcription and accuracy check. Participant data will be safely stored in a locked filing cabinet and on my computer, password protected. Only I and my graduate supervisor and advisor will have access to this information. *I will keep all the data for 5 years following the completion of the project, and will then be destroyed.* Confidentiality will be provided to the fullest extent possible by law.

Thank you.

Sincerely,

Samadhi Mora Severino”

## Appendix B

### INFORMED CONSENT FORM

**Date:**

**Study Name:** *The Supports Exist 'Why Can't We Access them?'* - Unveiling the Barriers in Accessing Home Care Services for the Caregivers of Children with Medically complex needs in Ontario

**Researchers:** Samadhi Mora Severino (Graduate student)  
Prof. Farah Ahmad (supervisor); Prof. Marcia Rioux (advisor)

**Sponsor(s):** York University

**Purpose of the Research:**

To investigate the experiences of parents/family members accessing home care supports in Ontario for their children with medically complex needs.. The study findings are anticipated to inform policy, practice and research to address the barriers in accessing home support care for children with medically complex needs.

**What You Will Be Asked to Do in the Research:**

You will be asked to participate in either a one-on-one semi-structured interview or a focus group about your experiences with accessing home care services for your child(ren) with medically complex needs. One-on-one interviews are expected to last 60-90 minutes and will take place at a mutually agreed time and place. Focus groups are expected to last 60-90 minutes and will take place at an accessible location. The interviews will be audio recorded and transcribed. You will be also asked to complete a brief descriptive survey on demographics and homecare support. The transcribed interview will be shared with you, if you desire so, for your review and any corrections you may want to suggest.

**Risks and Discomforts:**

This study is considered minimal risk. However, the possibility of feeling some emotional distress cannot be excluded due to the topic of research. At any time during the study, if you experience distress you are encouraged to speak to myself, the researcher, or discontinue your participation. Your participation is voluntary and you have the right to discontinue the interview at any time.

**Benefits of the Research and Benefits to You:**

There are no direct benefits to you by participating in this study. You will learn about existing resources for homecare support. The results of the study are anticipated to advance scholarly work and inform practice and policy in the area of homecare support for medically complex children in Ontario.

A small token of appreciation (i.e. \$10 gift card) will be offered in the anticipation to cover some of your travel expense.

**Voluntary Participation:**

Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to participate will not influence the nature of your relationship with myself, or York University either now, or in the future. If you decide to participate, you are free to not answer any question, or withdraw at any time without affecting any of these relationships or outcomes.

**Withdrawal from the Study:**

You can withdraw from the study at any point in time. There will be no penalty towards you. Should you decide to withdraw from the study, all data generated as a consequence of your participation shall be destroyed, whenever possible.

It is within your right to disclose what you want and when you want. You can also retract what you have said while in the interview/focus group, and when reviewing your transcript for accuracy.

**Confidentiality:**

All audio recordings and transcripts will be kept confidential and pseudonyms will be used for your anonymity. Your name or identifiable information will not appear in any report or publication of the research. Your data will be safely stored in a locked filing cabinet and on my computer, password protected, and only myself, supervisor, and advisor will have access to this information. *Data will be kept for 5 years following the completion of the project, and will then be destroyed.* Confidentiality will be provided to the fullest extent possible by law.

Confidentiality in focus groups: If you participate in a focus group, participants will be asked to maintain confidentiality; however, I cannot guarantee that the discussions and data disclosed in these group settings will remain confidential.

**Questions About the Research?**

If you have questions about the research in general or about your role in the study, please feel free to contact myself (647-643-2588/ [samadhi.mora@gmail.com](mailto:samadhi.mora@gmail.com)) or my Principal Supervisor, Professor Farah Ahmad ([farahmad@yorku.ca](mailto:farahmad@yorku.ca)). The proposal of this research has been reviewed and approved by the Ethics Review Committee of [Critical Disability Studies Graduate Program](#) and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the [Critical Disability Studies Graduate Program](#) Office (Tel: 416-736-2100 extension 44494; Email: [gradcds@yorku.ca](mailto:gradcds@yorku.ca)).

**Legal Rights and Signatures:**

I \_\_\_\_\_ (*Participants name*), consent to participate in” *The Supports Exist - Why Can’t We Access them? ’ - Unveiling the Barriers in Accessing Home Care Services for the Caregivers of Children with Medically complex needs in Ontario*” conducted by Samadhi Mora Severino. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. I understand that all information that I share for the study will be kept anonymous in any reports or publications based on this research. I have the choice to provide a “fake name” below in lieu of my real name. My signature below indicates my consent.

**To be filled out by the Participant:**

**To be filled out by the Principal Investigator:**

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Samadhi Mora Severino  
Name of Principal Investigator

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of Principal Investigator

\_\_\_\_\_  
Participant’s “fake name” (please print)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

**Oral Consent Script**

“Hello,

I, Samadhi Mora Severino, am a student in Mater’s of Arts program at the Department of Critical Disability Studies, York University in Toronto. I am conducting research on the experiences of parents/guardians of children with medically complex needs in accessing home care supports in Ontario. I am approaching you as a potential participant in this research and have provided you the written Informed Consent to read about the study details and ask any questions you may have.

The proposal of this research has been reviewed and approved by the Ethics Review Committee of [Critical Disability Studies Graduate Program](#) and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

I am inviting you as a willing parent/guardian to participate voluntarily in a semi-structured interview or a focus group that is expected to take 60-90 minutes. The

interviews will be audio recorded so that I can review and take further notes later for my research. Participants will be able to withdraw from the study at any time without penalty as it is their right.

In order to participate in this research you can provide written or oral consent. In the case of oral consent, you just need to tell me “I consent to be being part of the research” and provide me with either your real name or a fake name. Regardless, all names will be changed in the research and the final research report. Additionally, the interviews will be audio recorded so I can make additional notes later on. All data and recordings will be destroyed 5 years after the research has been completed.

Thank you,  
Samadhi Mora Severino”

## Appendix C

### Descriptive Survey

**Socio-demographic:** *please select only one response, unless specified otherwise.*

<ol style="list-style-type: none"><li>1. What is your gender? (a) Male                      (b) Female                      (c) Prefer not to say</li> <li>2. What age category do you fall into? (a) Less than 20 years (b) 21-30 (c) 31-40, (d) 41-50 (e) Over 50 years</li> <li>3. What is your current highest level of education? (a) Elementary school (b) High school graduate (c) Undergraduate Degree (d) Graduate Degree (i.e. MA and/or PhD) (e) Professional Degree (i.e. Medical or Law degree)</li> <li>4. What is your current employment status? (please select all that apply) (a) Part-time (b) Full time (c) Retired (d) On Social assistance (e) Accessing ODSP (f) Other, specify _____</li> <li>5. How would you describe your <u>current</u> intimate relationship? (please select all that apply) (a) Married/Common Law (b) Casual Relationship (c) Single (not in relationship) (d) Widowed (e) Divorced or Separated</li> <li>6. How many children do you have living at home? _____</li> <li>7. How would you rate your overall perceived physical and mental health? (a) Poor (b) Fair (c) Good</li></ol>
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(d) Very Good  
(e) Excellent

**Home Care Services**

1. What type of nursing services do you have access to via homecare? Please list all

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2. What CCAC catchment area do you live in? \_\_\_\_\_

3. What type of service funding model do you have?  
(a) Service coordinated model (b) Self- directed funding

4. How many years have you been receiving homecare nursing/PSW services? \_\_\_\_\_

5. How many hours per month do you receive these services? \_\_\_\_\_

6. What are the nurse's and PSW's responsibilities? List all

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7. Do you think the category of nursing services is right for your child?  
(a) Yes (b) No (c) Not Sure

If not or not sure, then please explain why:

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8. Do you think the amount of nursing hours you have is sufficient?  
(a) Yes (b) No (c) Not Sure

If not or not sure, then please explain why:

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9. Do you choose which hours to have a nurse, or are the hours chosen for you?

- (a) Never
- (b) Sometimes
- (c) Most of the time
- (d) Always

10. Can you change the hours at any time, given a week's notice?

- (a) Never
- (b) Sometimes
- (c) Most of the time
- (d) Always

11. Does the nurse/PSW accompany your child to appointments, play dates, events etc.?

- (a) Never
- (b) Sometimes
- (c) Most of the time
- (d) Always

If never or rarely, then please explain why:

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## Appendix D

### Descriptive Survey Tables

**Table 1:** Participant Socio-demographic characteristics (n = 7)

<p>Gender, % Female, 100%</p> <p><b>Age, %n</b> &lt;20, 0% 31- 40, 43% 41-50, 57%</p> <p>Highest Level of Education, % Undergraduate Degree, 85.7% Graduate Degree, 14.3%</p> <p>Employment Status, % Full Time, 28.6% Part Time, 14.3% Social Assistance, 14.3% Other, 42.8%</p>	<p>Relationship Status, % Married, 57.2% Divorced or Separated, 42.8%</p> <p>Number of Children 1 Child, 28.6 % 2 or More Children, 71.4%</p> <p><b>Perception of Overall Health, %</b> Poor, 28.5% Fair, 28.6% Good, 14.3% Very Good, 28.6% Excellent, 0%</p>
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**Table 2: Participant & Home Care Services (n = 7)**

Type of Home Care Services, % Nursing & PSW, 85.7% PSW only, 14.3%	Perceived amount of hours of nursing was sufficient, % Yes, 14.3% No, 85.7%
Level of Nursing (RN or RPN), % RPN, 100%	Being able to choose timing of service, % Sometimes, 28.6% Most of the time, 57.1%
Service Funding, % Service Coordinated Model ('Usual Care'), 85.7% Self-Directed Funding Model, 14.3%	Being able to change the hours, % Never, 42.8% Sometimes, 14.3% Most of the time, 14.3% Always, 28.6%
Years since service access, 3.78 years (mean)	
Amount of service per month, mean PSW, 37.4 hours Nursing, 99.4 hours	Nurse/PSW accompany their child(ren) to appointments, play dates, events etc., % Never, 71.4% Sometimes, 14.3% Most of the time, 0% Always, 14.3%
Perceived category of nursing was right, % Yes, 57.1% No, 42.9%	

## Appendix E

### Resources List

1. The Provincial Advocate Office for Children and Youth link:  
<https://provincialadvocate.on.ca/main/en/about/aboutus.cfm>
2. Facebook group links:
  - (a) Parents Advocating for Homecare Change in Ontario -  
<https://www.facebook.com/groups/1050595491678968/>
  - (b) Caregiving and Advocacy for Medically Complex Children-  
<https://www.facebook.com/groups/873097352747399/>
  - (c) Three To Be – PAL:  
<http://www.threetobe.org/pal/>  
<https://www.facebook.com/groups/173295489470728/>
  - (d) One More Thing: <https://www.facebook.com/groups/1MoreThing/>
3. Provincially Government Funded Assistance Programs for Children with Disabilities – Not income-based:
  - (a) Special Services at Home:  
<http://www.children.gov.on.ca/htdocs/English/specialneeds/specialservices.aspx>
  - (b) Enhanced Respite Funding:  
[http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/cspm\\_sec\\_3/3-11.html](http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/cspm_sec_3/3-11.html)
4. Provincially Government Funded Assistance Programs for Children with Disabilities – Income Based:
  - (a) Assistance for Children with Severe Disabilities (ACSD):  
<http://www.children.gov.on.ca/htdocs/English/specialneeds/disabilities.aspx>
5. Legal Services :
  - (a) Holland Bloorview Free Legal Advice:  
<http://hollandbloorview.ca/ClientFamilyResources/FamilyResourceCentre/ProBonoLawOntarioassistanceprogram>
  - (b) ARCH – Disability Law Centre: <http://www.archdisabilitylaw.ca/>
  - (c) Pooran Law Professional Corporation: <http://www.pooranlaw.com/>

6. Long Term Care Action Line through Ministry of Health and Long Term Care (MOHLTC) – Filing Complaints against CCAC and you can access a Mediator – Free of charge :  
[http://www.health.gov.on.ca/en/public/contact/ccac/ltc\\_actionline.aspx](http://www.health.gov.on.ca/en/public/contact/ccac/ltc_actionline.aspx)
7. Patient Ombudsman: <https://patientombudsman.ca/>
8. Health Services and Appeal Review Board: <http://www.hsarb.on.ca/>
9. Mental Health Supports/Counselling/Community Based Supports/ Family Support Groups:

(A) Toronto Area Resources

- Anishnawbe Health Toronto:  
<http://www.aht.ca/services-and-programs/services-offered>
- Woodgreen: <http://woodgreen.org/>
- Edgewest: <http://www.edgewest.ca/>
- Mothercraft: <http://www.mothercraft.ca/>
- Women's Connection Program (through Parkdale Community Health Centre): <http://www.pchc.on.ca/programs-services/womens-connection-program/>
- Black Creek Community Health Centre: <http://www.bcchc.com/>
- Sherbourne Health Centre: <http://sherbourne.on.ca/>
- Circle of Care: <http://www.circleofcare.com/>
- YorkTown Family Services:  
<https://www.yorktownfamilyservices.com/child-and-family-centre/>
- Rainbow Health Ontario: <http://www.rainbowhealthontario.ca/>

A) Ottawa Area Resources

- The Counselling Group: <http://thecounsellinggroup.com/>
- Bereaved Families of Ontario: <http://www.bereavedfamilies.net/>

- Inuit Family Resource and Health Promotion Centre:  
<http://tungasuvvingatinuit.ca/programs/>
- Family Services Ottawa: <http://familyservicesottawa.org/>
- Parent Resource Centre:  
[http://www.parentresource.ca/en/ottawaprc/Home\\_p555.html](http://www.parentresource.ca/en/ottawaprc/Home_p555.html)
- The Young/Single Parent Support Network of Ottawa:  
<http://www.ottawayoungparents.com/about-us/>
- Parents' Lifelines of Eastern Ontario: <http://www.pleo.on.ca/>
- Mothercraft: <http://mothercraft.com/>
- Orleans-Cumberland Community Resource Centre:  
<http://croc.ca/home/>
- 24 Hour Mental Health Crisis Line in Ontario:  
<http://www.mentalhealthhelpline.ca/Home/About>
- Parenting in Ottawa: <http://www.parentinginottawa.com/en/index.asp>

## **Appendix F**

### **Qualitative Interview Guide**

#### **Experiences of Accessing Home Care Supports**

1. How did you find out about home care supports?  
Probe: What did you do once you found out?
2. Did a medical professional or team of medical professionals help you and/or support your advocacy for home care supports?  
Probe: Was it challenging? Why? Was it helpful? Why?
3. How supportive was your CCAC case coordinator when wanting to access or to increase current support hours?  
Probe: How did you feel when you heard their reaction?  
Probe: What did you do next?
4. How would you describe your experience of negotiating the service level for your child?  
Probe: Was it challenging? Why?  
Probe: Was it positive? Why?
5. What positive experiences did you have with Ontario's Home Care System?
6. What made a difference did you think in relation to a positive vs. negative vs. constructive experience?

#### **Experiences of Appeal Process within Ontario's Home Care System**

1. Are you familiar with the appeal system for home care?  
Probe: If yes, could you explain. If not, let me explain a bit about this.
2. Have you ever been to the Health Appeal Board? What was the outcome? What was your experience?
3. How did you find out about the appeal process?
4. Did you know you could file a complaint with Long Term Action Complaint Line? Have you ever done this? If so, what was the response time? Did you find it helpful?
5. Have you sought help from any other resources outside the appeal system to advocate for the home care support that you need?  
Probes: advocacy networks/offices or MPPs or Patient Ombudsman or Ontario Ombudsman or The Provincial Advocate Office for Children & Youth?

#### **Societal and Cultural Discourse Barriers**

1. In your view, what were some of the reasons that you were not given access to home care supports that you were asking for?  
Probe: How did you feel about their reasoning?  
Probe: What happened next?
2. Did you feel that there was misunderstanding of being a parent and a caregiver?  
Probe: How does this make you feel?  
Probe: How challenging can this be?

3. Did you ever feel as if you were misunderstood?  
Probe: What do you think would have avoided the misunderstanding?
4. What were some of the common things you were being told repeatedly?  
Probe: What was some of the most challenging things to hear? Why?  
Probe: Can you tell me more about what that was like?

### **Economic and Political Barriers**

1. Would you be able to afford these services if they were not offered through OHIP?  
Probe: Can you tell me more about this?
2. Can you afford some of these supports? If so, what percent would you say?
3. Do you think these services should be offered as fee per income basis?  
Probe: If no, why? If yes, why?
4. How do you work and care for a child who has medically complex needs?  
Probe: Can you tell me more about your history of employment (i.e. finding new jobs, understanding employers, job loss) in relation to having a child who has medically complex needs?  
Probe: Can you tell me more what that was like?
5. Do you think the government should be responsible to support families of children with medically complex needs?  
Probe: If so, why? If not, why?
6. Do you feel there has been any changes to home care since the liberal government has been in power?  
Probe: What has the experience been like for you and your family by any (or if any) systemic changes to the home care system?
7. Were you part of home care services when the Harris Government created the current home care system?  
Probe: If so, what differences did you see? What were the impacts?

## Appendix G

### **The United Nations Universal Declaration of Human Rights, Relevant Articles**

(Where language in the UDHR is sexist, it has been replaced with gender neutral words, for example: “brotherhood” has been replaced with “kinship”)

#### **Preamble**

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of [humankind], and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if [people] is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, Therefore THE GENERAL ASSEMBLY proclaims THIS UNIVERSAL DECLARATION OF HUMAN RIGHTS as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

**Article 1.** All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of [kinship].

**Article 2.** Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

**Article 3.** Everyone has the right to life, liberty and security of person.

**Article 23.** (1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment. (2) Everyone, without any discrimination, has the right to equal pay for equal work. (3) Everyone who works has the right to just and favourable remuneration ensuring for [themselves] and [their] family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection. (4) Everyone has the right to form and to join trade unions for the protection of [their] interests.

**Article 25.** (1) Everyone has the right to a standard of living adequate for the health and well-being of [themselves] and of [their] family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

**Article 28.** Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

**Article 30.** Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

## Appendix H

### United Nations Convention on the Rights of the Child: Relevant ArticlesU

Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989  
entry into force 2 September 1990, in accordance with article 49

#### Preamble

The States Parties to the present Convention,

Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Bearing in mind that the peoples of the United Nations have, in the Charter, reaffirmed their faith in fundamental human rights and in the dignity and worth of the human person, and have determined to promote social progress and better standards of life in larger freedom,

Recognizing that the United Nations has, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status,

Recalling that, in the Universal Declaration of Human Rights, the United Nations has proclaimed that childhood is entitled to special care and assistance,

Convinced that the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community,

Recognizing that the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding,

Considering that the child should be fully prepared to live an individual life in society, and brought up in the spirit of the ideals proclaimed in the Charter of the United Nations, and in particular in the spirit of peace, dignity, tolerance, freedom, equality and solidarity,

Bearing in mind that the need to extend particular care to the child has been stated in the Geneva Declaration of the Rights of the Child of 1924 and in the Declaration of the Rights of the Child adopted by the General Assembly on 20 November 1959 and recognized in the Universal Declaration of Human Rights, in the International Covenant on Civil and Political Rights (in particular in articles 23 and 24), in the International

Covenant on Economic, Social and Cultural Rights (in particular in article 10) and in the statutes and relevant instruments of specialized agencies and international organizations concerned with the welfare of children,

Bearing in mind that, as indicated in the Declaration of the Rights of the Child, "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth",

Recalling the provisions of the Declaration on Social and Legal Principles relating to the Protection and Welfare of Children, with Special Reference to Foster Placement and Adoption Nationally and Internationally; the United Nations Standard Minimum Rules for the Administration of Juvenile Justice (The Beijing Rules); and the Declaration on the Protection of Women and Children in Emergency and Armed Conflict, Recognizing that, in all countries in the world, there are children living in exceptionally difficult conditions, and that such children need special consideration,

Taking due account of the importance of the traditions and cultural values of each people for the protection and harmonious development of the child, Recognizing the importance of international co-operation for improving the living conditions of children in every country, in particular in the developing countries,

Have agreed as follows:

## **PART I**

### **Article 1**

For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.

### **Article 2**

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

### **Article 3**

1. 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.

2. 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.

3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

**Article 4.** States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation.

**Article 5.** States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

**Article 6.** 1. States Parties recognize that every child has the inherent right to life.

2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

**Article 9.** 1. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.

2. In any proceedings pursuant to paragraph 1 of the present article, all interested parties shall be given an opportunity to participate in the proceedings and make their views known.

3. States Parties shall respect the right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests.

4. Where such separation results from any action initiated by a State Party, such as the detention, imprisonment, exile, deportation or death (including death arising from any cause while the person is in the custody of the State) of one or both parents or of the child, that State Party shall, upon request, provide the parents, the child or, if appropriate,

another member of the family with the essential information concerning the whereabouts of the absent member(s) of the family unless the provision of the information would be detrimental to the well-being of the child. States Parties shall further ensure that the submission of such a request shall of itself entail no adverse consequences for the person(s) concerned.

**Article 18.** 1. States Parties shall use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.

2. For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.

3. States Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from child-care services and facilities for which they are eligible.

**Article 23.** 1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

**Article 24.** 1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

(a) To diminish infant and child mortality;

(b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

(c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;

(d) To ensure appropriate pre-natal and post-natal health care for mothers;

(e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;

(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

**Article 27.** 1. States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.

2. The parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development.

3. States Parties, in accordance with national conditions and within their means, shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall in case of need provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing.

4. States Parties shall take all appropriate measures to secure the recovery of maintenance for the child from the parents or other persons having financial responsibility for the

child, both within the State Party and from abroad. In particular, where the person having financial responsibility for the child lives in a State different from that of the child, States Parties shall promote the accession to international agreements or the conclusion of such agreements, as well as the making of other appropriate arrangements.

**Article 41.** Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of the child and which may be contained in:

- (a) The law of a State party; or
- (b) International law in force for that State.

## **PART II**

### **Article 42**

States Parties undertake to make the principles and provisions of the Convention widely known, by appropriate and active means, to adults and children alike.

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1/ The General Assembly, in its resolution 50/155 of 21 December 1995 , approved the amendment to article 43, paragraph 2, of the Convention on the Rights of the Child, replacing the word “ten” with the word “eighteen”. The amendment entered into force on 18 November 2002 when it had been accepted by a two-thirds majority of the States parties (128 out of 191).

## Appendix I

### United Nations Convention on the Rights of Persons with Disabilities: Relevant Articles

#### **Article 3: General principles**

The principles of the present Convention shall be: (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (b) Non-discrimination; (c) Full and effective participation and inclusion in society; (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (e) Equality of opportunity; (f) Accessibility; (g) Equality between men and women; (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

#### **Article 7: Children with disabilities**

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. 2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. 3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

#### **Article 10: Right to life**

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

#### **Article 17: Protecting the integrity of the person**

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

#### **Article 19: Living independently and being included in the community**

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; (c) Community services and facilities for the general

population are available on an equal basis to persons with disabilities and are responsive to their needs.

**Article 21: Freedom of expression and opinion, and access to information**

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by: United Nations Convention on the Rights of Persons with Disabilities Page 12 of 28 <http://www.un.org/esa/socdev/enable/rights/convtexte.htm> 6 December 2006 (a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost; (b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions; (c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities; (d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities; (e) Recognizing and promoting the use of sign languages.

**Article 23: Respect for home and the family**

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that: (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized; (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided; (c) Persons with disabilities, including children, retain their fertility on an equal basis with others. United Nations Convention on the Rights of Persons with Disabilities Page 13 of 28 <http://www.un.org/esa/socdev/enable/rights/convtexte.htm> 6 December 2006 2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities. 3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities

and their families. 4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents. 5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

### **Article 25: Health**

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. In particular, States Parties shall: (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes; (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons; (c) Provide these health services as close as possible to people's own communities, including in rural areas; (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care; (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner; (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability

### **Article 32: International cooperation**

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia: (a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities; (b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices; (c) Facilitating cooperation in research and access to scientific and technical knowledge; (d) Providing, as appropriate, technical and economic

assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies. 2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

## **Appendix J**

### **Ontario Human Rights Code**

Ontario's [\*Human Rights Code\*](#), the first in Canada, was enacted in 1962. The *Code* prohibits actions that discriminate against people based on a protected *ground* **in** a protected *social area*.

Protected grounds are:

- Age
- Ancestry, colour, race
- Citizenship
- Ethnic origin
- Place of origin
- Creed
- Disability
- Family status
- Marital status (including single status)
- Gender identity, gender expression
- Receipt of public assistance (in housing only)
- Record of offences (in employment only)
- Sex (including pregnancy and breastfeeding)
- Sexual orientation.

Protected social areas are:

- Accommodation (housing)
- Contracts
- Employment
- Goods, services and facilities
- Membership in unions, trade or professional associations.

## Appendix K

### Home Care and Community Services Act, 1994:

#### *Purposes of Act*

1. The purposes of this Act are,

- (a) to ensure that a wide range of community services is available to people in their own homes and in other community settings so that alternatives to institutional care exist;
- (b) to provide support and relief to relatives, friends, neighbours and others who provide care for a person at home;
- (c) to improve the quality of community services and to promote the health and well-being of persons requiring such services;
- (d) to recognize, in all aspects of the management and delivery of community services, the importance of a person's needs and preferences, including preferences based on ethnic, spiritual, linguistic, familial and cultural factors;
- (e) to integrate community services that are health services with community services that are social services in order to facilitate the provision of a continuum of care and support;
- (f) REPEALED: 2011, c. 1, Sched. 6, s. 4 (1).
- (g) to promote equitable access to community services through the application of consistent eligibility criteria and uniform rules and procedures;
- (h) to promote the effective and efficient management of human, financial and other resources involved in the delivery of community services;
- (i) to encourage local community involvement, including the involvement of volunteers, in planning, co-ordinating, integrating and delivering community services and in governing the agencies that deliver community services; and
- (j) to promote co-operation and co-ordination between providers of community services and providers of other health and social services;
- (k) REPEALED: 2011, c. 1, Sched. 6, s. 4 (2).

## PART III BILL OF RIGHTS

### *Bill of Rights*

3. (1) A service provider shall ensure that the following rights of persons receiving community services from the service provider are fully respected and promoted:

1. A person receiving a community service has the right to be dealt with by the service provider in a courteous and respectful manner and to be free from mental, physical and financial abuse by the service provider.
2. A person receiving a community service has the right to be dealt with by the service provider in a manner that respects the person's dignity and privacy and that promotes the person's autonomy.
3. A person receiving a community service has the right to be dealt with by the service provider in a manner that recognizes the person's individuality and that is sensitive to and responds to the person's needs and preferences, including preferences based on ethnic, spiritual, linguistic, familial and cultural factors.
4. A person receiving a community service has the right to information about the community services provided to him or her and to be told who will be providing the community services.
5. A person applying for a community service has the right to participate in the service provider's assessment of his or her requirements and a person who is determined under this Act to be eligible for a community service has the right to participate in the service provider's development of the person's plan of service, the service provider's review of the person's requirements and the service provider's evaluation and revision of the person's plan of service.
6. A person has the right to give or refuse consent to the provision of any community service.
7. A person receiving a community service has the right to raise concerns or recommend changes in connection with the community service provided to him or her and in connection with policies and decisions that affect his or her interests, to the service provider, government officials or any other person, without fear of interference, coercion, discrimination or reprisal.
8. A person receiving a community service has the right to be informed of the laws, rules and policies affecting the operation of the service provider and to be informed in writing of the procedures for initiating complaints about the service provider.
9. A person receiving a community service has the right to have his or her records kept confidential in accordance with the law. 1994, c. 26, s. 3 (1).

### **Service Provisions under Ontario's "Home Care and Community Services Act"**

As of October 1<sup>st</sup> 2015, nursing and personal support worker monthly allocation maximums are the following:

- Personal Support Worker (PSW) 120 hours for the first 30 days of service and 90 hours per month going forward
- Registered Nurse (RN) is 230 hours per 30 days.
- Registered Nurse (RN) mixed with Registered Practical Nurse(RPN) is 258 hours

per 30 days.

- Registered Practical Nurse (RPN) is 284 hours per 30 days

## Appendix L

### Recommendations

#### **For MOHLTC, LHIN, & CCAC**

*1. Reactive not Proactive Approach with Home Care Supports*  
Accessing timely home care supports- specifically, nursing and PSW- is essential to prevent health issues and family breakdown for the parents and their children with medically complex needs. This was emphasized by all the participants. One participant said “Whenever a child is born with a disability or later develops a disability, make sure the right supports are in place rather than not having support for years”.

*2. More Support, Less Advocacy*  
All the participants discussed they want to feel supported when accessing home care supports and part of that support is having to advocate less. They no longer want to feel home assessment as a fearful process in which they could possibly lose hours but it should feel as collaborative experience where the families feel supported. Another participant said, “We want to feel supported [but] not always feel like [that]. We have to advocate for home care supports. We shouldn’t have to constantly feel in fear of losing support hours”.

*3. Information on What Home Care Supports Exist, Different Forms of Appeals & Compliant Line*  
The interviews reveal that information on what home care support exists, internal appeal, external appeal, and MOHLTC Action Complaint Line needs to be widely available for these caregivers to access. The concerned caregivers/parents need to be informed of this information and to be able to access it. Additionally, policy manuals need to be available online for unpaid caregivers to access; and information on where to find this information seems not clear and not widely available at this present time. The participants were conveyed with different information across different CCACs. As one participant stated, “whether it’s because I didn’t search for it or I felt that it wasn’t widely communicated, I feel like just making sure that process and the policies are transparent because I find that different people have different amount of care depending on where they live, who their coordinator is.” Another participant said “I feel like there should be more information that’s accessible and available to people”.

*4. Listen to Us When We’re Asking for Home Care Supports*  
A key finding is parents’ desire that service providers should listen to them actively for the home care supports they ask. Participants questioned the assumptions of providers as their requests and needs were sometime viewed as ‘habitual’ and minimized. Additionally, when unpaid caregivers receive home care supports they also lose their privacy at home because someone is there for some part of the day or overnight, and by no means having home care support is a luxury. Another participant articulated “you need to listen to the parents...if they tell you need a nurse... you should do everything in your

power to make it happen.... Cause really, who really wants a nurse in their house just for fun? You know? If we're asking for it, we need it".

#### 5. *Come to our homes*

Most of the participants mentioned they wanted policy decision makers from the MOHLTC and CCAC directors to come into their homes to spend a day with their families for them to see what their lives are like. In hopes, this would add valuable knowledge to construct policies. One participant said "I'd love to see someone come into my house for one day and see what we go through. And then tell me we don't qualify for anything. Or Just come see what it is, for one day, what parents have to deal with from the school system, health system, from our own work, from everything".

#### 6. *Direct Funding*

Two participants already had direct funding and some parents voiced they wanted to access to Direct Funding. Direct Funding is when CCAC provides the funding dollars to parents to purchase their own support works (i.e. PSW and Nursing) rather than going through usual care (where CCAC sends agency nurses and PSWs to the families homes). Families want more flexibility with their services and to choose who they want to hire to meet the needs of their child with medically complex needs.

#### 7. *Maximum Legislated Hours are Not meeting the Needs of Children with Medically Complex Needs*

The current legislated maximums for PSW and Nursing are not meeting the needs of the children with medically complex needs. Participants voiced how they wanted a say in how funds were allocated, with the ability to have input into what type of care was most relevant to their child's needs. The current hours are not meeting the needs of their children and they want to provide them with the support they require to participate in the community. These children all required 1:1 support at all times. As Sarah stated "Right now the funding is very limited to hiring a certain amount of hours of service providers... uh if a lump sum was given and then given the ability to parents to use it as they wish, they would be able to somehow get more hours and more help than if they were just limited by a certain number of hours".

#### 8. *Too Much Discretion with No Parameters Causing Inequities within Home Care*

Many of the participants voiced concern over how much discretion CCAC had, and how too much professional discretion was causing inequitable access to home care supports. The inequities were linked to multiple factors, such as: the specific CCAC worker assigned to a family, the specific CCAC case coordinator and directors, and similar diagnostic complexity among children served by CCAC. There needs to be clearer guidelines with concrete examples of what discretion a CCAC has and how discretion needs to be supportive towards these families. As Sarah said "Policymakers need to make it little more clear on how much services certain people would get automatically, and not

just leave it up to CCAC to have the complete say in who gets the services or not...cause right now the policy is pretty open and leaves the whole freedom to CCAC to decide”.

### *9. Allowing Home Care Staff into Hospitals*

The baseline care for children with medically complex needs means keeping them stable despite fragile status. When they are hospitalized, they require a higher amount of care. Participant parents expressed a need to be able to access their home care staff within hospital for several reasons. The first reason being hospitals cannot provide 1:1 care to their children who require high baseline care while hospital nurses provide the acute care. Home care nurses could provide baseline care within hospital settings as well. Secondly, accessing home care nurses and PSWs can alleviate parent/caregivers from stress and to prevent family breakdown because the stress of having to be in too many places (i.e. at home caring for other children at home, bring their other children to the hospital, running a household, errands) and being at the hospital is very taxing on parents. Thirdly, the system need to continue to support unpaid caregivers and amount of care they provide for children with medically complex needs in Ontario. As Sara mentioned “they’re (CCAC) not allowing nurses and caregivers to be present in the hospital, which I think completely does not make sense...CCAC claims its duplication of service...but it’s not duplication of services because the hospital nurses they are there to follow what the doctor says, but they’re not there to care for the child”.

### ***For Parents of Children with Medically Complex Needs***

#### *1. To keep advocating and try not to give up*

Caregiving for a child with medically complex needs is hard enough as it is. Don’t give up advocating for your child and try not to give up. You have the right to access these supports and talk to other caregivers in similar situations to learn from one another. Don’t take ‘no’ for an answer from Ontario’s Home Care System. One participant said “Don’t be afraid to ask questions. Caregivers in general have to help each other and figure out the system, you can’t take no for an answer”.

#### *2. Get Everything in Writing*

It is important for parents to get everything in writing from CCAC as this allows for a level of accountability and transparency for families. Always get everything in writing either through mail or email. Another participant said “One of the most important lessons I’ve learnt is to get everything in writing”

#### *3. We need to Work Together to Improve the Quality of Life of Our Children*

Parents of children with medically complex needs need to work together to try to fix Ontario’s Home Care System as it is very fragmented. There needs to be collective strive to improve the lives of their children together – rather than individually. One participant stipulated “Well I don’t want to give to you because it might take away from my child”

that kind of thinking has to stop. We have to be in it together to get what's best for our children”

*4. Don't wait to get Home Care Supports*

Parents should try to get home care access before the situation causes burn out. Any human being can only tolerate so much and there is no shame in asking for help. The ability to care as a parent is hard enough, but add the caregiving role and it becomes so much harder. If someone makes you feel bad or shameful asking for help then you should question their moral character. You are not doing anything wrong by asking for home care supports. One participant stated “don't wait to get help, don't wait till the situation is out of control and things have gone into crisis. Advocate, don't give up.” Always asks for help and anybody who makes you feel demoralized for asking for help, question their ethics and their position for doing this...perhaps they were not in the right position and they're not entitled to their job”.