

ECHOES OF REFORM: THE EXCELLENT CARE FOR ALL ACT AND
PSYCHIATRIC PATIENT ADVOCACY IN ONTARIO

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Abstract:

The passage of the *Excellent Care for All Act* (ECFAA) in June 2010 marked a significant juncture for healthcare reform in Ontario, aiming to enhance standards, optimize resources, and reduce costs across hospitals. One significant responsibility mandated under *ECFAA* was the requirement for a Patient Declarations of Values (PDoVs). This study delves into the foundational underpinnings of the PDoV development process, drawing from Mad Studies theory and the contemporary landscape of patient advocacy. I examine the integration of patient embodied knowledge in these PDoVs, while simultaneously identifying conspicuous absences by unpacking the assumptions within "patient engagement" and its role in shaping the medico-legal discourse surrounding patient rights within the psychiatric milieu. This study reveals challenges for advocacy within psychiatric settings and underscores the importance of revitalizing praxis for capacity building in community activism in order to shape the future landscape of mental healthcare provision and the safeguarding of patient rights.

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I am the first person in my family to earn a postgraduate degree. My parents' generation, and the one before them, lived under a fascist leader who catered to the wealthy, suppressed the media, and left much of the population impoverished and uneducated. Pushing beyond this historical legacy has been challenging at times. The opportunity to have pursued an education is a privilege and one that I do not take for granted.

TABLE OF CONTENTS

Abstract:	ii
Acknowledgements	iii
TABLE OF CONTENTS	v
List of Tables	viii
INTRODUCTION	- 1 -
Background	- 3 -
Statement of the Problem	- 5 -
Research Questions	- 9 -
Nomenclature and the Politics of Words	- 11 -
Overview of the Chapters.....	- 16 -
Chapter 1	- 20 -
PATIENT ACTIVISM AND THE STRUGGLE FOR	- 20 -
INDEPENDENT ADVOCACY	
1.1 The Right to Choose.....	- 20 -
1.2 “Engagement” before the Excellent Care for All Act.....	- 26 -
1.3 Patient Voice: Policy, Community 1960 - 2000	- 30 -
1.4 Building a Framework.....	- 33 -
1.5 Patient Government, Councils, and Human Rights	- 37 -
1.6 From Degeneracy to Civic Patienthood: Recovery Discourse.....	- 41 -
1.7 The New Panopticon: Patient Engagement.....	- 46 -
CHAPTER 2	- 53 -
MEDICO LEGAL BORDERLANDS	- 53 -
2.1 Patient Bill of Rights and Care Covenants.....	- 53 -
2.2 Un-charted: Patient Bills of Rights	- 54 -
2.3 The “Excellent Care for All Act” (ECFAA).....	- 59 -
2.4 Quality Committees.....	- 61 -
2.5 Quality Improvement Plans.....	- 64 -
2.6 Patient Relations.....	- 65 -

2.7 Patient Declaration of Values.....	- 66 -
2.8 The Psychiatric Patient Advocate Office	- 68 -
2.9 The Coalition for an Independent Psychiatric Patient Advocacy Office	- 71 -
Chapter 3	- 76 -
THEORETICAL FRAMEWORKS.....	- 76 -
3.1 What is Mad Studies?.....	- 76 -
3.2 Mad Activist Praxis – Mobilising Human Rights	- 77 -
3.3 Mad /Service User Epistemology.....	- 82 -
3.4 Epistemic injustice	- 86 -
3.5 Sanism	- 88 -
3.6 Legislation: What does Mad Studies have to do with it?	- 91 -
3.7 The Outsider Within - Standpoint	- 94 -
CHAPTER 4	- 103 -
THE RESEARCH PATH.....	- 103 -
4.1 Thematic Analysis.....	- 104 -
4.2 Limitations of research.....	- 106 -
4.3 Reading the Data	- 108 -
4.4 Procedures	- 110 -
Step1. Data Familiarization	- 111 -
Step 2. Systematic Data Coding	- 113 -
Step 3. Generating initial themes from coded and collated data	- 113 -
Step 4. Developing and reviewing themes	- 116 -
Step 5 Refining, defining and naming themes.....	- 118 -
Chapter 5	- 122 -
FINDINGS	- 122 -
5.1 Theme 1. Responsibilization and Presumptive Contracts.....	- 123 -
5.2 Theme 2. Respectability	- 130 -
5.3 Theme 3: Patient Subjectivity	- 134 -
5.4 Theme 4 Law as Elusive	- 139 -
Chapter 6	- 144 -
DISCUSSION	- 144 -

6.1 Responsibilization and Respect.....	- 145 -
6.2 Patient Subjectivity - No “Self” Left Behind.....	- 150 -
6.3 Law as Elusive	- 153 -
6.4 Theory and the Return to Mad Praxis	- 155 -
Chapter 7	- 160 -
CONCLUSION	- 160 -
7.1 Summary of Findings	- 160 -
7.2 Implications	- 163 -
7.3 Final Reflections	- 166 -
BIBLIOGRAPHY.....	- 169 -
Legislation.....	- 169 -
International Conventions	- 170 -
Jurisprudence.....	- 170 -
Debates	- 171 -
Secondary Materials	- 171 -
Government Documents.....	- 193 -
Parliamentary Documents	- 194 -
Other Documents.....	- 195 -
News Sources	- 199 -
APPENDIX A	- 201 -
Hospitals.....	- 201 -

List of Tables

Table 1	Hierarchy Tree map chart
Table 2	Summary of Major Themes
Table 3a	Theme Responding, Obligation
Table 3b	Theme Patient Responsibility
Table 3c	Theme Patients Participating
Table 4	Theme Respectability
Table 5	Theme: Patient Subjectivity
Table 6	Theme: Law as Elusive

INTRODUCTION

*So what's so revolutionary in what we have now?*¹

In May 2010, during a debate pertaining to *The Excellent Care for All Act (ECFAA)*² and its directive on Patient Declaration of Values, France G elinas³, a Member of the Select Committee on Mental Health and Addictions, inquired about what was so revolutionary about the proposition of hospitals creating their own Patient Declaration of Values (PDoVs).⁴ Admittedly, in the realm of governance, the establishment of robust values holds great importance and forms the bedrock upon which an organization stands, ensuring its alignment with the requirements of the community it serves. But as G elinas remarked a month before the legislation received royal assent:

We are surrounded by hospitals where we are. Go down University Avenue, walk into any one of those mega-hospitals we have down here, go into any washroom or any elevator and you will see that they all have a set of values. They have a mission, they have a vision, and they share it with everybody. So what's so revolutionary in what we have now?⁵

Indeed, in Toronto, walking down the city's hospital corridor on University Avenue, south of College Street, the public is habitually met with one inspirational hospital slogan after another, emblazoned across banners on buildings. Hospitals strengthen their corporate communications strategies and their brand reputation using multiple public platforms to better communicate their

¹ Ontario, Legislative Assembly, Official Report Journal of Debates (Hansard) 39th Parl.2nd Sess.No26. (May 4 2010) at 1194 (France G elinas). Online: https://www.ola.org/sites/default/files/node-files/hansard/document/pdf/2010/2010-05/house-document-hansard-transcript-2-EN-04-MAY-2010_L026.pdf [<https://perma.cc/VK9H-3VA7>].

² *Excellent Care for All Act*, 2010, SO 2010, c 14.

³ France G elinas is a New Democratic member of the Legislative Assembly of Ontario, representing the Nickel Belt riding since 2007.

⁴ *Official Report Journal of Debates* (Hansard) 39th Parl.2nd *Supra* note 1.

⁵ *Official Report Journal of Debates* (Hansard) 39th Parl.2nd *Supra* note 1.

institutional vision and values with internal and external stakeholders. These serve the purpose of galvanizing employees internally and building trust with patients and members of the public around a hospital's vision and values.

As someone who works within a large psychiatric hospital in Toronto, Ontario, patient values, care, engagement and human rights have always been central concerns to me for over twenty years in my advocacy work. Initially, my exploration into this realm of patient values and patient engagement was fuelled by a sense of professional and academic curiosity, particularly amidst a backdrop of diminishing resources for independent service user/survivor organizations as well as advocacy organizations such as the Psychiatric Patient Advocacy Office. In respect to patient engagement, Johannesen notes:

I don't know the origin story of today's patient engagement enterprise – I don't know who named it, or who the first volunteer was, or where the first advisory committee convened. But I'm fairly certain that patients didn't invent it. Patients were not wandering around looking to form committees or give helpful advice to researchers. Patient engagement, as a program, is defined, implemented, and managed by institutions, not by patients.⁶

The motivation behind my inquiry stemmed from determination to understand the escalating enthusiasm, fervour, and allocation of resources directed towards burgeoning initiatives of “patient engagement” and the political milieu in which these initiatives are emergent. Previously, I investigated similar phenomena in the mental health sector, where various historical trends emerged and then waned, all ostensibly aimed at improving patient care and involvement in their

⁶ Jennifer Johannesen, “The trouble with patient and public involvement (PPI)” – keynote at Cochrane Colloquium 2018” (September 26, 2018) online: Jennifer Johannesen <https://johannesen.ca/2018/09/the-trouble-with-patient-and-public-involvement-ppi-keynote-at-cochrane-colloquium-2018> [https://perma.cc/RPZ3-CGBP]

treatment.⁷ I became aware that as the discourse on patient engagement gained prominence, other narratives were undergoing a conspicuous disappearance. Specifically, the organizations and political activism that defined the last half-century from psychiatric service users were undergoing a transformative shift, ultimately heading towards erasure. In light of this, this thesis explores how discourses of patient engagement within the *Excellent Care for All Act (ECFAA)*⁸ and its mandate on Patient Declaration of Values (PDoV) statements constitute a newly constructed medico –legal lexicon shaping patient voice and inevitably rights. I start first by providing some preliminary background information about the *ECFAA*,⁹ a summary of the research questions explored throughout this thesis, a critical discussion on nomenclature and an overview of the chapters that will follow.

Background

In June 2010, the Legislative Assembly of Ontario voted unanimously in favour of the *Excellent Care for All Act (ECFAA)*.¹⁰ At the time, the Minister of Health Deb Matthews claimed that the new legislation would increase the standard of care, provide better value for the money invested, and reduce overall system expenses.¹¹ As required by this new law all hospitals were directed to have a Patient Declaration of Values (PDoV) by June 8, 2011 (i.e. 12 months after Royal Assent) and make these PDoV statements available to the public. Hospitals were not obligated to create a

⁷ During my undergraduate studies, I conducted and produced a comprehensive research paper examining the emergence of "Therapeutic Communities" in psychiatric care during the 1950s and 1960s, as well as the development and adoption of the recovery model in Canada in the early 2000s. Trends in psychiatry have been extensively documented in texts such as "Great And Desperate Cures: The Rise and Decline of Psychosurgery and Other Radical Treatments for Mental Illness" by Elliot S. Valenstein, and "Desperate Remedies Psychiatry's Turbulent Quest to Cure Mental Illness" by Andrew Scull.

⁸ *Excellent Care for All Act, Supra* note 1.

⁹ *Excellent Care for All Act, Supra* note 1.

¹⁰ *Excellent Care for All Act, Supra* note 1.

¹¹ Deb Matthews, "Letter from the Minister of Health and Long-Term Care" (Dec. 2012) 15 *Healthcare Quarterly* Special Issue 1.

PDoV if they had already demonstrated the publication of some other similar and relevant document, for example, a patient bill of rights, a philosophy of care, or patient code of conduct.¹² Having said this, as described in the government guidance document, PDoVs are meant to be created through public consultation, and be distinct from other organizational documents such as mission, vision and or organizational statements and PDoVs are meant to explain what Ontario patients should expect from their health care institutions, ideally with the subsequent goal of advancing patient-centred care.¹³

In March 2019 (eight years after PDoV statements were introduced) the Deputy Premier and Minister of Health and Long-Term Care, Christine Elliott, along with Julie Drury, Chair of the Minister's Patient and Family Advisory Council, further issued a press release with information on the provincial government's version of a Patient Declaration of Values for Ontario that included the values of: respect and dignity, empathy and compassion, accountability, transparency, equity, and engagement – similar ideals to those found in many hospital PDoVs. This province-wide declaration did not specify how it was to be used, by whom, or its relationship to the PDoVs already in place at each hospital.¹⁴

¹² Ontario Ministry of Health and Long Term Care, *Guidance Document for the Declaration of Values ECFAA Requirement*, (Ontario: November 2010) at 2 ss 2.2 online: www.health.gov.on.ca/en/pro/programs/ecfa/legislation/patientvalue/guide_patient_dec_e.pdf [<https://perma.cc/YA25-B6LX>]

¹³ *Ibid* at ss 1.2

¹⁴ Ontario, Minister's Patient and Family Advisory Council. *Press Release: Ontario's Government for the People Affirms Patient Values and Health Care Expectations* (Queen's Printer for Ontario: March 08, 2019) <https://news.ontario.ca/en/release/51450/ontarios-government-for-the-people-affirms-patient-values-and-health-care-expectations> [<https://perma.cc/XNB2-9UNB>]

Statement of the Problem

In this thesis, I investigate two potential issues associated with PDoVs in the context of psychiatric hospitals. First, given that the historical work of social movement activism by psychiatric patients played a key role in the development of accountability, human rights and legal reform for patients in Ontario, determining whether PDoVs further advance “quality care,” and human rights bears investigation given that this history of patient advocacy predates the legislation.¹⁵ The strongest advocates of the rights and needs of psychiatric patients’ were patients and ex-patients themselves who fought for legal and governmental reforms to prohibit lobotomies, electroshock, sterilisation, restraints, seclusion and a host of neurological symptoms or conditions such as tardive dyskinesia, produced by long-term use of psychiatric drugs.¹⁶ For value statements to justify the time and resources invested in them they should be something more than a compass¹⁷ in health services and offer clarity about the choices and rights of the service provided before those rights are disregarded, rather than after. I further contend that when statutory language requires decision-makers to consult (in this case, with patients) the issue of whether they have done so and what counts as (adequate) consultation is one that can and should align with the principles of procedural justice. Before the legislation was enacted, it is important to note that value statements had already been articulated in prior reports by consumer/survivor

¹⁵ For further reading on social movement history and advocacy please see: Geoffrey Reaume. “Mad Activists and the Left in Ontario, 1970s to 2000” (2021) in *Voices in the History of Madness* at 307 and Geoffrey Reaume. “Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients’ activism in North America” (2002) 25:4 *International Journal of Law and Psychiatry* at 405.

¹⁶ Please see, Harvey Savage and Carla McKague. *Mental Health Law in Canada*. (Toronto: Butterworths, 1987) for an overview of mental health law concerns in Ontario and Bonnie Burstow and Don. Weitz. *Shrink Resistant: The Struggle Against Psychiatry in Canada*. (Vancouver, New Star Books, 1988) a milestone publication that articulated the experiences of patients in psychiatric institutions.

¹⁷ The Patient, Family and Caregiver Declaration of Values for Ontario, drafted by the Minister’s Patient and Family Advisory Council states that is intended to serve as a “compass” for the individuals and organizations who are involved in health care and that it is not intended to establish, alter or affect any legal rights or obligations. Please see: Ministry of Health. Patient, “*Family and Caregiver Declaration of Values for Ontario*” (2021) <https://www.ontario.ca/page/patient-family-caregiver-declaration-values-ontario> [<https://perma.cc/8LJK-HAPP>]

organizations.¹⁸ Unlike in previous years where service user organizations were able to govern their own funding, today, service users are constrained in their ability to continue social justice, intellectual work, and build from their own earlier engagement and advocacy efforts. As such, it is important to “take stock,” as Beresford argues, of the supports needed to empower service user led organizations.¹⁹

I discuss the state of service user participation in the mental health sector as part of my research and provide background on patient participation in Ontario in my literature review given that patients and ex-patients were integral to discussions and mobilisation of human rights, essentially by pitting subaltern knowledge against psychiatric knowledge.²⁰ But how did the opposition between patient experience and medical expertise arise? Critiques about psychiatry’s theoretical structure and treatments began in the twentieth century with what was termed as a “revolt from above,” initiated by psychiatrists within their own ranks²¹. This contrasted with the “revolt from below,” represented by groups in service user/survivor movements²². While there

¹⁸ Mary O’Hagan, Heather. McKee and Robyn. Priest. “Consumer survivor initiatives in Ontario: Building for an equitable future: Report for CSI Builder Project” (June, 2009). Ontario Federation of Community Mental Health and Addiction Programs.

¹⁹ Peter Beresford, “PPI or User Involvement: Taking stock from a service user perspective in the twenty first century” (2020). 6:36 *Res Involv Engagem*

²⁰ Linda Morrison. *Talking back to psychiatry: the psychiatric consumer/survivor/ex-patient movement*. (New York: Routledge 2005) at 17.

²¹ For example, South African psychoanalyst David Cooper, psychoanalysts Ronald D. Laing, Thomas Szasz and physician Franco Basaglia.

²² There were certainly individual patients who complained about psychiatric detention prior to the 20th century for instance Elizabeth Packard wrote about her wrongful committal in June 1860. Please see: Elizabeth Packard, *Marital Power Exemplified in Mrs. Packard's Trial, and Self-Defence from the Charge of Insanity*. (Chicago: Clarke and Co. 1870). As another example, William Belcher, who was confined for 17 years in a madhouse, published an account in 1796 about “the disabilities of real insanity” when he wrote: “I have been bound and tortured in a straight waistcoat fettered crammed with a bullocks horn, and knocked down, and at length declared a lunatic by a Jury that never saw me. Please see: William Belcher, *Address to humanity: Containing, a Letter to Dr. Thomas Monro: A receipt to make a lunatic and seize his estate; and a sketch of a true smiling hyena* (1796). at 4.

https://archive.org/details/bim_eighteenth-century_belchers-address-to-hum_belcher-wm-william_1796/mode/2up
[<https://perma.cc/6LVA-NXZC>]

were overlaps among these revolts, they were/are distinct.²³ In the early social movement mobilization, patients questioned both the legal power of psychiatrists to detain and treat individuals and the medicalization of madness.²⁴ While certain areas within psychiatric fields have shifted, subaltern knowledge remains a critically relevant discussion today given resistance to this knowledge is prevalent, and revisionist historical narrative have led to the erasure or sanitization of knowledge, rendering past practices more palatable. This process frequently disregards the complexities of complicity and ongoing harm.²⁵

As noted by McCann, a significant aspect of the historical function of legal mobilization has been to grant social movements access to formal institutional authority and this access is made especially impactful through litigation, thereby rendering it consequential.²⁶ Despite the purported positive intentions of the *ECFAA*²⁷, and the development of a declaration of values, there remains a lack of clarity regarding how principles of stakeholder engagement and deliberation influence hospital practices and foster the realization of rights. This is further complicated if we think about separating the voices of service user advocacy groups (which have a long history) from the kind of intimate feedback individual patients can sometimes share in

²³ Nick Crossley. "RD Laing and the British anti-psychiatry movement: a socio-historical analysis" (1998) 47 Soc Sci Med.

²⁴ Please refer to the U.S.'s *Madness Network News* and Canada's *Phoenix Rising: The voice of the psychiatrized*, which provides detailed instances of advocacy and activism.

²⁵ For further reading please see: Ameil Joseph. "The subjects of oblivion Subalterity, sanism, and racial erasure" in Peter Beresford and Jasna Russo eds. *The Routledge International Handbook of Mad Studies* (New York Routledge, 2021) at 135 as well as, Jijian Voronka' discussion on service users/peer workers as subjects of subalternity in "Troubling Inclusion: The Politics of Peer Work and 'People with Lived Experience' in Mental Health Interventions." (PhD, Ontario Institute for Studies in Education University of Toronto, 2015) Unpublished at pp 212.

²⁶ Michael McCann. "Law and Social Movements: Contemporary Perspectives" (2006) 2:1. Annual Review of Law and Social Science at 33.

²⁷ *Excellent Care for All Act*, *Supra* note 1.

meetings. How do hospitals discern between the two and who holds the responsibility for making this judgment?²⁸

Secondly, as part of this research, I draw from my standpoint working as an advocate for over twenty years in a service user led organization funded within Canada's largest mental health and addiction teaching hospital. From this position, I have observed how the *ECFAA*²⁹ has influenced this particular hospital site and how access to advocacy has shifted over the years in practice. This hospital in particular has a broad employee base, with numerous other competing frameworks or training requirements³⁰ that inform the work staff do; PDoVs are not central. Given abundant competing clinical goals and pressures for staff, "value statements" and corporate slogans are designed to elicit a sense of efficacy, control, and direction. These statements can unify and provide focus, however while these statements garner some energy for a period of time, there is no evidence that they guarantee better quality of care, or rights protection for hospital patients³¹. While PDoV statements can perhaps be useful tools for creating ethical, patient-centred organizations, their effectiveness depends on how well patients were consulted in the process, how cogent, well-written, and clear they are, and most importantly, the degree to which it is possible to carry them out in daily health care activities and

²⁸ Similarly, as Abelson notes, it is unreasonable to expect patients to fully grasp what information is being sought from them and in what format, particularly when adequate communication and support are lacking. For further discussion, see Julia Abelson's work, which focuses on public engagement with health systems in various roles, including patients, community members, voters, and taxpayers. Abelson, a professor in the Department of Health Research Methods, Evidence, and Impact at McMaster University, has extensively explored the challenges and tensions associated with patient engagement.

²⁹ *Excellent Care for All Act*, *Supra* note 1.

³⁰ Here, I am referring to, for example, staff collective agreements with the Ontario Public Service Employees Union (OPSEU) or the Ontario Nurses Association (ONA), as well as training programs such as Workplace Violence Prevention, Trauma-Informed De-escalation for Safety and Self-Protection (TIDES) Certification, web-based medical record-sharing application technology, and Infection Prevention and Control, among other hospital initiatives.

³¹ Allie Peckham et al. "Putting the Patient First: A Scoping Review of Patient Desires in Canada" (2021)16:4 Health Care Policy at 56.

staff practices that impact patients particularly in psychiatry where individuals are legally detained involuntarily.³²

Research Questions

In response to the imperatives outlined in the *ECFAA*³³, which emphasize accountability and transparency in healthcare delivery, and the increasing discourse surrounding "patient engagement,"³⁴ I undertook this analysis of PDoVs from nine psychiatric hospitals in Ontario. These nine facilities included: The Royal (Brockville), St. Joseph's Healthcare (Hamilton), Providence Care Hospital (Kingston), Parkwood Institute (London), Waypoint Centre for Mental Health (Penetanguishene), Southwest Centre for Forensic Mental Health Care (St. Thomas), St. Joseph's Health Care Group (Thunder Bay), The Centre for Addiction and Mental Health (Toronto) and Ontario Shores Centre for Mental Health Sciences (Whitby). The objective was to identify recurring themes in these statements and to compare them across institutions. Specifically, the study aimed to explore several key questions: What common discursive themes are evident across the PDoVs of the nine hospitals? How do these themes reflect a prioritization of human rights, the patient advocate office, or other mechanisms for rights protection? Furthermore, what discursive patterns and indicators of patient voice, identity, and engagement emerge from the analysis of these PDoVs?

³² For further reading on patient views on Canadian healthcare system please see: A. Peckham et. al *Patients' views of the Canadian healthcare system*. (Toronto: North American Observatory on Health Systems and Policies 2020) and Joaquin Zuckerberg, "Jurisdiction of Mental Health Tribunals to Provide Positive Remedies: Application, Challenges and Prospects" (2011) 57:2 McGill LJ at 267. Zuckerberg argues that civil mental health courts in Canada lacks the authority to rule on ongoing treatment and supervision issues and does not generally address the right to adequate mental health care.

³³ *Excellent Care for All Act*, *Supra* note 1.

³⁴ Please see: Paula, Rowland et al. "Learning from Patients: Constructions of Knowledge and Legitimacy in Hospital-Based Quality Improvement Programmes." (2018) 40:3 *Studies in Continuing Education* at 337. Here the authors discuss the emergence of patient engagement and contend that organisations are learning from specific constructions of patient subjectivities in the form of patient advisers rather than from patients as a whole.

This research holds significance in light of the recognition that patient value documents have been, or continue to be, regarded as important by the Ontario government, which mandates that hospitals create a "declaration of values" for patients following public consultation.³⁵ The existing literature addressing these correlations is notably limited, underscoring the importance of further inquiry into this area.³⁶ This study also explores the interplay between theoretical frameworks, examining the established lineage of patient embodied knowledge and advocacy alongside the absence of these theoretical underpinnings in PDoV development processes. It asks how the introduction of this legislative directive has impacted patient advocacy overall, and the activities of the already established advocacy provisions such as the Ontario Patient Advocate Office.

My concluding findings indicate that while PDoVs advocate for patient participation in healthcare and emphasize personal responsibility and respect, they construct patient subjectivity around a narrow self-governance narrative that lacks historical context. Despite outlining rights, the accessibility and understanding of these rights remain shadowed, particularly with the diminished role of the Psychiatric Patient Advocate Office (PPAO). Moreover, PDoVs marginalize critical theoretical frameworks, particularly those related to law, disability, and psychiatric disability (Mad Studies), reflecting an underexplored dimension in their promotion and discourse.

³⁵ Office of the Auditor General of Ontario, "2010 Annual Report" (2010) (Queen's Printer for Ontario) at 370. https://www.auditor.on.ca/en/content/annualreports/arreports/en10/2010ar_en.pdf [<https://perma.cc/SZ4F-5XYR>]

³⁶ For further discussion on how hospitals consider operationalizing PDoVs please see, Julie Finnigan, et al. "Empowering Patients and Families to Create, Inform and Endorse a New Patient and Family Declaration of Values." (2022) 25:2 Healthcare quarterly (Toronto, Ont.) as well as Erica Bridge et al "Using Patient Value Statements to Develop a Culture of Patient-Centred Care: a Case Study of an Ontario, Canada Hospital." (2016) 3:2 Patient experience journal.

Nomenclature and the Politics of Words

*AN testified on her own behalf. She testified that her experience was one of a survivor of psychiatry and psychiatric treatment.*³⁷

Words carry weight and meaning as for instance, with individuals like AN, who during her consent and capacity board hearing, identified as a “survivor of psychiatry” opposing her psychiatrist's diagnosis of schizophrenia. She expressed feeling victimized by the psychiatric system due to past hospitalizations, restraints, and forced treatment with psychiatric medications, leading to post-traumatic stress.³⁸ One way to control people is by choosing and using certain words and language over others. For Foucault, governmentality and language combined are intellectual techniques that allow for specific types of actions and outcomes.³⁹ In this thesis, it became evident that addressing nomenclature was unavoidable when discussing service users’ experiences with psychiatry and law. The terminology chosen by service users is far from neutral; it is deeply political and significantly influences discussions of PDoVs, shaping the norms, actions, and outcomes they produce..

Historically, there have always been many terms used to describe ‘Mad people’ as treatments and diagnoses of mental illness have always been controversial, contested and debated.⁴⁰ Identity politics has evolved over time, spurred by an increasing acknowledgment within communities and academic discourse that individual identity encompasses more than just mental illness. Instead, it encompasses a complex interplay with other identities, including but

³⁷ AN (Re), 2010 CanLII 68909 (ON CCB).

³⁸ *Ibid.*

³⁹ Michel Foucault, *Ethics: Subjectivity and Truth. Essential Works of Michel Foucault, 1954–1984*. Vol. 1. (New York: New Press 1997) at 67.

⁴⁰ Geoffrey Reaume, “Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients’ activism in North America” *Supra* note 15 at 405.

not limited to race, socioeconomic class, sexual orientation, and citizenship status.⁴¹ Similar to other liberation movements, the 'Mad liberation movement' of the 1960s evolved in language and vocabulary. This evolution is comparable to the changing landscape of identity terms within the LGBTQ2S movement. For many years “queer” was considered pejorative, but in the 1980s the term was proudly reclaimed by members of LGBTQ2S communities, particularly during the years of AIDS activism and protest.⁴² New identity categories were also added to the range of sexual orientation and gender identity categories to include trans, two spirit, non-binary, gender nonconforming and pansexual. Similarly, the disability movement has been very open to accepting new terminology to denote the identities of members. Some individuals with disabilities have opted to refer openly to themselves as "crip" as a show of defiance and a positive reclamation of disability in opposition to “handicapped.”⁴³ Some advocacy organizations have opted to call themselves, “People First” representing the voice of people with intellectual and developmental disabilities.⁴⁴ At an international level, the Convention of Rights of Persons with Disabilities (CRPD) uses “persons with disability” and “psychosocial disabilities” interchangeably.⁴⁵ “Neurodiversity” was first introduced as an alternate way of understanding and (re)naming autism in 1998.⁴⁶ Today, the term neurodiversity includes conceptual intersections with other identities, as for example, with the term, “neuroqueer” to

⁴¹ Mark Anthony Castrodale, “Mad matters: a critical reader in Canadian Mad Studies” (2015) 17:3 *Scandinavian Journal of Disability Research* at 284.

⁴² Terry Goldie, "Queer Nation?" (Eleventh Annual Robarts Lecture delivered at the Robarts Centre for Canadian Studies, York University, March 4, 1997).

https://yorkspace.library.yorku.ca/xmlui/bitstream/handle/10315/24017/rl_goldie.pdf?sequence=1
[<https://perma.cc/R7Q8-JTKY>].

⁴³ Robert McCruer, *Crip theory: cultural signs of queerness and disability* (New: York University Press, 2016) at 34

⁴⁴ Please see: People First Canada at <https://www.peoplefirstofcanada.ca/about-us/history>.

⁴⁵ United Nations, Office of the High Commissioner, *End of Mission Statement by the United Nations Special Rapporteur on the rights of persons with disabilities on her visit to Canada* (12 April 2019)

<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=24481&LangID=E>
[<https://perma.cc/M2MF-E2GJ>].

⁴⁶ Judy Singer. *NeuroDiversity: The Birth of an Idea* (2016) at 9.

describe how neurodiversity and queer identity intertwine.⁴⁷ Words carry weight and meaning, especially for individuals like AN. During her consent and capacity board hearing, she emphasized her identity as a survivor of psychiatry, resisting her treating psychiatrist's diagnosis of schizophrenia

My literature review on the early years of patient and ex-patient organizing draws from the activism and labour of the 1980's and 1990s "psychiatric survivor" and mental health or, psychiatric "consumer" movement. Provincially resourced organizations were called consumer survivor initiatives – "CSIs" for short. "Mad" also appeared more readily in Toronto, replacing what was initially called Psychiatric Survivor Pride Day⁴⁸ with "Instance of Resistance" in 2000 to "Psyche Survivor Pride Week" in 2001 and "Mad Pride" from 2002 onward.⁴⁹ In Toronto in 2005, the Mad Students Society established itself as one of the first independent peer support and advocacy group for students in Ontario who identified as having had contact in the mental health system and by November 2007, members of the listserv initiated conversations⁵⁰ about Mad Studies.⁵¹ Mad Studies was further developed in the Disability Program at Toronto Metropolitan University⁵², and later York University and has grown internationally as an important field.⁵³ In Ontario, approximately 2005 onward terminology shifted once again

⁴⁷ Nick Walker. Walker. *Neuroqueer heresies : notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. (Autonomous Press, 2021).

⁴⁸ Lilith Finkler, "Psychiatric Survivor Pride Day: Community Organizing with Psychiatric Survivors." (1997) 35:3:4, *Osgoode Hall Law Journal* at 763.

⁴⁹ Geoffrey Reaume, "A history of psychiatric survivor pride day during the 1990s" (July 14, 2008) 374 *CSINFO Bulletin* https://csinfo.ca/bulletin/Bulletin_374.pdf [https://perma.cc/T5MF-KMLM].

⁵⁰ Richard Ingram's claim to having coined the term "Mad Studies" is inaccurate. Ingram participated in an online student listserv known as the Mad Students Society (established in 2005) where discussions around the concept of Mad Studies, as well as student experiences within this framework, were already underway before Ingram made his assertions.

⁵¹ Mad Students Society List serve November 12th 2007 discussion about Mad Studies.

⁵² Formerly known as Ryerson University.

⁵³ Please see: Alex Gillis, "The rise of Mad Studies" Nov. 03 2015, University Affairs

adopting the UKs use of the term “service user” as a means to describe people who were using mental health services (in addition to using other intersecting health care resources such as addiction services, social assistance, ACT teams etc.).⁵⁴

As language undergoes changes over time, it is essential to recognize its lack of political neutrality and its potential to impact different spheres of influence or power dynamics. For instance, in January 2012, during preparations for the Empowerment Council's constitutional challenge,⁵⁵ I underwent cross-examination by the Attorney General's office.⁵⁶ I was asked a number of questions regarding my, or our organization's use of the terms “consumer –survivor” and the implication of this terminology. I was asked questions whether I was “philosophically opposed to community treatment orders (CTOs).”⁵⁷ In my view, the questions aimed to gauge whether the organizations perspective and language use aligned with conventional or alternative viewpoints; the scrutiny reflected a desire to ensure alignment with prevailing standards, practices, and goals of mental health.

The words that service users choose and how they prefer to identify themselves matters so much so that in 2011, in Toronto, upon direction of the CEO of the Centre for Addiction and Mental Health (CAMH) in partnership with members of the CAMH Empowerment Council, a “catalytic conversation” entitled, “What’s in a Name: A conversation about language, labels and

<<https://www.universityaffairs.ca/features/feature-article/mad-studies/#comments> [<https://perma.cc/GFL4-KV3C>] and Peter Beresford, “Mad Studies brings a voice of sanity to psychiatry” Oct 7 2014 *The Guardian* <https://www.theguardian.com/society/2014/oct/07/mad-studies-voice-of-sanity-psychiatry> [https://perma.cc/HG24-BXYB].

⁵⁴ Peter Beresford, “Service user”: regressive or liberatory terminology?” (2005) 20:4 *Disability & Society*, at 469.

⁵⁵ *Thompson and Empowerment Council v. Ontario*, 2013 ONSC 5392 <https://canlii.ca/t/g0js1>.

⁵⁶ *Thompson v. Attorney General of Ontario*, 2011 ONSC 2023, Cross examination of Lucy Costa January 12, 2012.

⁵⁷ Fortunately, my counsel swiftly clarified that my personal opinions on Community Treatment Orders (CTOs) were irrelevant to the challenge. As an advocate, my role is to represent the feedback and concerns of patients, particularly those subject to CTOs. Additionally, I have facilitated focus groups over the years with individuals who have been subject to CTOs, ensuring that their voices are heard.

identity” was organized and held.⁵⁸ The event was framed as being a “catalytic” conversation, to openly listen to, debate, discuss and strategize how CAMH should take up what people want to call themselves, but in the end there is no evidence that the information gathered from the audience would steer the hospital towards a more inclusive vernacular in regards to mental illness. Over time, CAMH has broadened its terminology regarding sexual orientation and gender identity, possibly due to political pressure from groups like LGBTQ2S and Indigenous communities. Additionally, at the time of writing this thesis, efforts are underway to remove racist language from patient chart documentation. This shift towards inclusivity is also evident in initiatives like Shkaabe Makwa, launched in 2018 to support First Nations, Inuit, and Métis individuals with service provision. ‘Shkaabe Makwa’ was uniquely named for how the service team and elders recognize their work as “having been walking with the Bear for years” and the foundation of their service ethos is that they will “seek help and guidance from the “Spirit World.”⁵⁹

Although there is *some* adaptability as identity and recognition politics evolve, there is minimal variation in the available options for service users to identify themselves if their self-labeling falls outside the medical/pathology paradigm. This raises questions about how such identities align with or diverge from the framework of "engagement" and the declaration of patient values, a topic that I repeatedly considered throughout this research. For the purposes of this thesis, I will mainly use the term “service user” given that this is a term predominantly used in contemporary scholarship, with the caveat that I also use a variety of additional terms

⁵⁸ Catherine Zahn CEO CAMH, Jennifer Chambers, Coordinator, Empowerment Council, and Kwame McKenzie, Medical Director, Health Equity and Deputy Director, Schizophrenia Program at CAMH. Catalytic Conversation: What’s in a name? (Toronto: October 19, 2011).

⁵⁹ See: Shkaabe Makwa Online: < <https://www.camh.ca/en/driving-change/shkaabe-makwa>> [<https://perma.cc/AN68-PW7F>]

contingent on how they appear in historical texts, law, PDoV documents, first-person accounts, and in Mad Studies scholarship.

Overview of the Chapters

This thesis argues that the discourses within the *Excellent Care for All Act* (ECFAA)⁶⁰ and its Patient Declaration of Values statements create a new vocabulary that shapes patient voice, activities, and rights. This approach overlooks the contributions of past service users, assumes a form of equity in engagement processes, and in so doing mitigates ableist and sanist guilt by performing a ruse of progress and “equity making” through the inclusion of service users in the operationalization of PDoV activities. These performative acts of care can often obscure deeper, more prejudicial attitudes and systemic issues to instill temporary fixes that do not question incarceration, the increasing criminalization of psychiatric disability, or the coercive aspects of mental health services. As service users remain under resourced and a politically weak constituency, marginalization of their interests has had limited political consequences, as seen in the glacial pace of mental health reform leaving fragmented accountability and legal reform.⁶¹ The thesis unfolds over seven chapters.

Chapter 1

Beyond this introductory initial chapter, I begin in Chapter One, with a review of the relevant literature highlighting the context and history of service user participation in the development of Ontario mental health policy and legal mobilisation to highlight the arc of patient activism. I

⁶⁰ *Excellent Care for All Act*, *Supra* note 1.

⁶¹ Please see: Mary E. Wiktorowicz, Kaitlin Di Pierdomenico, Neil J. Buckley, Steve Lurie, Gail Czukar “Governance of mental healthcare: Fragmented accountability, (2020) 256 *Social Science & Medicine* for an an analysis on Canada’s health law and policy evolved to inhibit resources and, C. Tess Sheldon on the need for an interpretive lens of equality in: C Tess Sheldon, “Entangling Liberty and Equality: Critical Disability Studies, Law and Resisting Psychiatric Detention” (2023) 46:1 *Dalhousie Law Journal*.

begin in the late 1970s to 2020 to demonstrate how alternative patient identities were formed and leveraged to resist and address human rights within and outside of the mental health system. This period covers a brief overview that predates and complicates contemporary legislative directives to encourage consultation with patients as a step in creating a process for developing a “high quality, accessible, equitable, patient centred, health care system”⁶².

Chapter 2

In chapter two, I present a brief overview of the human rights literature pertaining to psychiatric patients in Ontario, thereby situating the contemporary trajectory within its historical context. Subsequently, I discuss the *ECFAA*⁶³ and its tenets as delineated in the statute. I conclude this chapter with a description of how the Liberal government sought to divest the office of the Psychiatric Patient Advocate, a once robust and active agency for rights protection and how the advocacy landscape has shifted since the adoption of the *ECFAA*.⁶⁴

Chapter 3

Chapter three highlights my research theoretical framework. I discuss Mad Studies and standpoint epistemology as the guiding frameworks in which I have grounded my research. As Mad Studies is significant to law on a variety of topics, its scope as a field and contribution is characterised by its underlying questions regarding the role of legislation in upholding, rejecting, or challenging inequity, ableism and sanism⁶⁵ in legal and medical practices. I unpack and

⁶² *Excellent Care for All Act*, *Supra* note 1 preamble.

⁶³ *Excellent Care for All Act*, *Supra* note 1.

⁶⁴ *Ibid*

⁶⁵ For a comprehensive understanding of sanism please see: Michael L. Perlin, “On "Sanism" (1992) 46 *SMU L. Rev.* at 373.

discuss some key concepts that inform Mad Studies and apply them to the research findings in the discussion in chapter six. Additionally, I incorporate Mad Studies and standpoint theory into my research design and analytic process to understand the *ECFAA*⁶⁶ and PDoV statements, along with the underlying assumptions, practices and knowledge production associated with them.

Chapter 4

In chapter 4, I discuss the research path and methods for data collection and data analysis conducted through thematic analysis in order to uncover and refine the themes embedded in the PDoVs of nine hospitals chosen. Thematic analysis offers a form of pattern recognition and a means to make sense of information within the PDoV text and as Braun and Clarke suggest, thematic analysis is a foundational method of gathering data and capturing the meaning within that data.⁶⁷

Chapter 5

Chapter five presents the research findings derived from my thematic analysis and serves to unpack and elucidate various themes inherent in the Patient Declaration of Values (PDoVs). Through this analysis, I identify and expound upon the key themes emerging from the dataset, providing a discussion about the discourses and values embedded within the PDoVs and their implications.

⁶⁶ *Ibid*

⁶⁷ Victoria Braun and Victoria Clarke, "Using thematic analysis in psychology" (2006) 3:2 *Qualitative Research in Psychology*

Chapter 6

I began my research by examining the stated objectives of the *ECFAA*⁶⁸, particularly focusing on the mandate for PDoVs to reflect patient values and examining how these declarations compare with one another. Additionally, I explored how these declarations influence patient voice and identity. Drawing from the theoretical framework established in chapter three, I applied it to the identified themes to discuss their implications. This analysis delves into the relationship between these themes and hospital language, aspirations, rights discourse, autonomous patient governance, and the role of the psychiatric patient advocacy office.

Chapter 7

I conclude this chapter with an overview of the findings, highlighting the implications for Mad Studies and the necessity of examining how institutions shape patient experiences and legal rights. Finally, I emphasize the urgent need to renew collective community building, champion independent advocacy, and ensure that the voices of service users resonate meaningfully in both healthcare and legal reform.

⁶⁸ *Excellent Care for All Act*, *Supra* note 1

Chapter 1

PATIENT ACTIVISM AND THE STRUGGLE FOR INDEPENDENT ADVOCACY

*But for far too long people in psychiatric institutions particularly, who are some of the most vulnerable people in our society, have not had the benefit of independent advocacy*⁶⁹

This chapter aims to contextualize this study within the current scholarly literature on patient and ex-patient rights mobilization. This literature review consists of four sections. First, I discuss the emergence of service user activism in the United States and its relevance to Canada and Ontario. I follow this with a discussion on the historical developments of key moments in the rising tide of patient inclusion in Ontario from 1960 to the 2000s. This is followed by a discussion of how patients have changed from being passive recipients of custodial care to “recovered”⁷⁰ subjects and civic actors in healthcare. The emergence of patient engagement initiatives in the healthcare sector is covered in the final section. I conclude with a discussion that provides an overview of the evolution of human rights protections within the psychiatric context.

1.1 The Right to Choose

This chapter begins with an examination of the local historiography pertaining to service user/survivor participatory initiatives within the jurisdiction of Ontario. The early efforts of the Ontario government to involve service users and patients in policy development were shaped by "group politics," which refers to the collective political activities and social movement initiatives that began in the late 1970s and continued onwards.⁷¹ These group political movements provided

⁶⁹ Ontario, Legislative Assembly, Standing Committee on Administration of Justice “Committee Transcript” (February 13, 1992) (Don Weitz) at 1530. https://www.ola.org/en/legislative-business/committees/administration-justice/parliament-35/transcript/committee-transcript-1992-feb-13#P667_214818 [<https://perma.cc/C699-P4F4>].

⁷⁰ Jijian Voronka, "Storytelling beyond the psychiatric gaze: Resisting resilience and recovery narratives" (2019) 8:4 Canadian Journal of Disability Studies at 25.

⁷¹ By group politics, I denote the work of actual movements that reach beyond the designation of “interest groups” and include individuals who may feel there are structural barriers in facing change with government. For further

an opportunity outside of electoral mechanisms for the development of politicized identities among psychiatric patients and ex-patients, independent of the dominant psychiatric and medical discourse. This process acted as a catalyst for the emergence of novel subjectivities and epistemologies, while also later providing avenues for legal mobilization. In contemporary contexts, the evolution of this historical trajectory has notably contributed to the maturation of the academic discipline recognized as Mad Studies.⁷² Serving as the theoretical foundation informing the analysis of my research data, Mad Studies encapsulates the interdisciplinary framework that has emerged from this historical continuum. To comprehensively grasp the evolutionary trajectory of psychiatric patient organizing in Ontario, it is important to acknowledge the influential role exerted by movements in the United States, particularly those that emerged to resist and reject psychiatric treatments.⁷³ I discuss this historical context to emphasize and later analyze how the language used in the patient declaration of value statements (PDoVs) is often focused on individual experiences rather than collective organizing, and may not address human rights issues effectively.

The Insane Liberation Front (ILF), established in 1970 in Portland, Oregon, represented an early manifestation of group activism within the domain of mental health advocacy. Its membership was restricted to individuals who had received a diagnosis of mental illness or had

reading on group politics and social movement organising, please see Miriam Smith (ed.), *Group Politics and Social Movements in Canada* (Toronto: University of Toronto Press, 2014).

⁷² Robert J Menzies, Geoffrey. Reaume, and Brenda A. LeFrançois. *Mad Matters : A Critical Reader in Canadian Mad Studies*. (Toronto: Canadian Scholars' Press, 2013).

⁷³ Before the internet became ubiquitous, the UK boasted a rich tradition of social movement organizing. Yet, due to its geographical closeness, Ontario often found its most fervent allies in political struggles across the border in the United States.

experienced institutionalization.⁷⁴ The ILF was no longer active by 1971 but some of its founding members moved on to create organizations in Boston and New York the following year. From this group, one of the best-known American activists for psychiatric patient human rights during that era was Judi Chamberlin. In 1966, after experiencing a miscarriage, Chamberlin sought psychiatric help and admitted herself to a psychiatric institution. There, she was diagnosed with schizophrenia and involuntarily committed. The abuse she endured during her hospitalization motivated her to take political action.⁷⁵ Chamberlin played a key role in founding the Mental Patients' Liberation Front in Cambridge, Massachusetts. She later authored the Front's seminal text, *On Our Own*, published in 1978.⁷⁶ It is this text that is recognised as having captured the shared concerns of psychiatric patients about treatments and for inspiring the mobilisation of psychiatric patient movement organising in both the USA and Canada.⁷⁷ Chamberlin's legacy encompasses advocating against coercive practices and medical authoritarianism in psychiatric services, promoting alternatives to institutionalization for mental health crises, and empowering service users to run their own programs and services.⁷⁸

These movements engendered a transformation in the individual experiences of psychiatric treatment, fostering a collective subjectivity.⁷⁹ In effect, they exerted pressure on

⁷⁴ Mary Ziegler, *Beyond Abortion : Roe V. Wade and the Battle for Privacy*. (Cambridge Massachusetts: Harvard University Press, 2018) at 93.

⁷⁵ Fred Pelka. *What have we done: an oral history of the disability rights movement* (Boston University of Massachusetts Press 2012) at 285.

⁷⁶ Judi Chamberlin, *On Our Own: Patient controlled alternatives to the mental health system* (New York: McGraw-Hill Book Company, 1978).

⁷⁷ Wendy Chan, Dorothy E Chunn, and Robert Menzies. *Women, Madness and the Law*. (United Kingdom: Taylor & Francis Group, 2005) at 249.

⁷⁸ Chamberlin *Supra* note 76 at 86 -106.

⁷⁹ Please see: Phil Brown, "Public Policy and the Rights of Mental Patients" (1982) 6:1 *Mental Disability L Rep* at

⁵⁵. Please also see, Kathryn Church, (1993) *Breaking down/Breaking through: Multi Voiced Narratives on Psychiatric Survivor Participation in Ontario's Community Mental Health System*, Doctoral Dissertation, University

both the medical establishment and governmental processes to see, include and legitimate the experiences of mental health service users⁸⁰. Within the context of burgeoning social activism and the push for psychiatric institutions to heed patient voices, advocacy movements found enhanced efficacy in asserting the centrality of "lived experiences" in shaping mental health services and legal reform agendas.⁸¹ And it was this assertion that underscores the significance of prioritizing these experiences as pivotal rather than peripheral in the discourse surrounding mental health treatment provision and legal frameworks, particularly concerning matters such as consent to treatment. The Mental Patients' Liberation Front as well as other emergent groups⁸² such as the Network against Psychiatric Assault in 1972 in San Francisco began mobilising legally for access to the medical records as well for the right to choose and consent to treatments in psychiatric care.⁸³

In her work titled *Beyond Abortion*⁸⁴ Ziegler elucidates the provocative strategies employed by "The Centre for the Study of Legal Authority and Mental Patient Status," a small organization comprising civil libertarian lawyers. This group frequently contributed to editions of Madness Network News (MNN)⁸⁵ detailing their legal endeavours aimed at advocating for the

of Toronto and then published as *Forbidden Narratives: Critical Autobiography as Social Science*. (London: Routledge, 1995) at 128.

⁸⁰ Over time members of the movement began to demand involvement in various professional forums: conferences, legislative hearings, boards, committees. They made presentations to the President's Commission on Mental Health in the 1970s. They demanded inclusion in Community support Program conferences sponsored by the National Institute of Mental Health (NIMH). *Ibid* at 129.

⁸¹ Geoffrey Reaume, "Mad Activists and the Left in Ontario, 1970s to 2000" *Supra* note 15 at 315.

⁸² Much of the social movement organising of current and former psychiatric patients in Ontario grew from similar streams of thought and vision in US groups such as the Insane Liberation Front in Portland 1970, the New York City Mental Patients Liberation Project in 1971, the 1971 Mental Patients Liberation Front in Boston and the Network Against Psychiatric Assault in 1972 in San Francisco.

⁸³ Ziegler *Supra* note 74 at 93.

⁸⁴ *Ibid*.

⁸⁵ Madness Network News (MNN) began as a newsletter in the San Francisco Bay Area in 1972. MNN was founded by ex-patients and grew into a prolific quarterly publication with a broad international reach until 1986. Please see: Madness Network News (San Francisco: Madness Network News, 1972).

right to consent to treatment and combating coercive practices within psychiatric settings. One of their strategies was to leverage arguments in *Roe v Wade*⁸⁶ as a means to advocate for legislation that would grant patients the right to refuse psychiatric treatment. Zielgler recounts that arguing for a right to refuse treatment would necessitate courts respect the decision-making capacity of the mentally ill, much as the *Roe v Wade*⁸⁷ decision had done when it acknowledged the competence of women in their capacity to make prudent judgements. In *Roe*⁸⁸ the reference to "the right of privacy" reminded that there are restrictions on what the government can do to someone's mind, even in the name of "treatment." Activists aimed to challenge these stereotypes regarding mental patients' dependence by demonstrating their capacity to make decisions, similar to how the *Roe* Court acknowledged women's ability to control their reproductive lives. By extending the right to privacy beyond abortion, former patients proposed perspectives on who could effectively exercise the right to choose, despite facing a mental health issue.⁸⁹ These groups emerged as influential social activists and agents of change highlighting the way in which these ideas later circulated to Canada and Ontario, but the predominance of white activists within these movements often overlooked the impact of whiteness and racism within their own human rights, mental health and disability advocacy efforts.

In her book, "*Black Disability Politics*," Schalk meticulously compiles historical materials from the Black Panther Party and the National Black Women's Health Project to address the omissions in advocacy and social justice history with respect to the history of

⁸⁶ *Roe v. Wade*, 410 U.S. 113 (1973).

⁸⁷ *Ibid.*

⁸⁸ *Ibid.*

⁸⁹ Ziegler *Supra* note 74 at 83.

psychiatric disability activism.⁹⁰ According to Schalk, the Black Panthers frequently collaborated with and/or supported mental disability and psychiatric activist groups to call attention to abuses occurring in psychiatric hospitals (as well to other carceral sites such as prisons). Organizations including the California Mental Health Coordinating Council, the Committee Opposing Psychiatric Abuse of Prisoners, the Network against Psychiatric Assault, the Coalition against Forced Treatment, and the Black Panther Party collaborated on multiple occasions⁹¹. Numerous articles about mental illness and antipsychiatry activism by the Black Panther Party were published in the news magazine. For instance, one edition includes highlights of retained attorney Fred J. Hiestand's testimony at the California Senate committee on the Health and Welfare regarding the development of the Centre for the Study of Violence to be constructed at the University of California; his testimony was a sharp rebuke and criticism of the Centre's proposal for psychosurgery⁹² in its pilot research.⁹³ Attention to race and other intersectional issues in the history of mobilisation also characterize a coalescing of various interest groups, emergent tensions and advocacy goals. Starting from the early 1970s, individuals who had experienced hospitalization for mental illness began to recognize that, akin to other marginalized groups, they too were often subjected to stigmatizing language and faced discrimination. Sensing and subsequently organising for change, former psychiatric patients

⁹⁰ Sami Schalk. *Black Disability Politics*. (Durham: Duke University Press, 2022).

⁹¹ *Ibid* at 50.

⁹² Psychosurgery (also known as psychiatric surgery, psychiatric neurosurgery) is a medical procedure that removes destroys or severs healthy brain tissue in the interest of curing or ameliorating mental disorders.

⁹³ Black Panther Party, "Attorney exposes U.C.L.A. Violence Centre" *Black Panther Intercommunal News Service* (Vol. 6 Saturday June 23 1973) at 13 online: <https://www.marxists.org/history/usa/pubs/black-panther/10%20no%206%201-20%20jun%2023%201973.pdf> [<https://perma.cc/JTX8-4QGW>].

started to regularly mutually strategize, assert their rights and abandon their role as powerless victims.⁹⁴

Over the past sixty years, service user legal and political work has evolved through various struggles and shifts, moving from the ex-patient movement to antipsychiatry to consumerism, with different forces shaping and challenging it.⁹⁵ Like Canada, what has remained constant is the call for a more responsive and socially just system, regardless of gender, race, practices, or disability, while also advocating for the protection of the rights to self-determination against the coercive power of the state and treatment system.

1.2 “Engagement” before the Excellent Care for All Act

Over six decades in Ontario, the articulation of psychiatric patient demands for inclusion in mental health policy, legislation, and research has become a poignant narrative driven by a strong ambition to revolutionize provincial mental health practices, laws, and policies.⁹⁶ Early psychiatric patient social movement organizing was a significant and necessary precursor to understanding how present-day calls for patient inclusion and representation of patient perspectives in the mental health sector (i.e. hospitals and mental health agencies) has evolved, diverged and been reconstituted if not appropriated into contemporary “patient engagement” discourse.

⁹⁴ Fredrick J. Frese and Wendy Walker Davis “The consumer-survivor movement, recovery, and consumer professionals” (1997) 28:3 *Professional Psychology: Research and Practice* at 244.

⁹⁵ Athena, McLean, “The Mental Health Consumers/Survivors Movement in the United States.” In Teresa Scheid, & Tony N Brow, eds *A Handbook for the Study of Mental Health. United States:* (Cambridge: Cambridge University Press, 2009) at 462.

⁹⁶ Liat Ben-Moshe L. “The tension between abolition and reform”. In M.E. Nagel and A.J. Nocella, eds. *The End of Prisons: Reflections from the Decarceration Movement* (New York: Rodopi, 2013) at 83.

Like the U.S., in Ontario the mid-seventies was a time, current and ex-psychiatric patients began to meet and create self-help groups outside of psychiatric institutions.⁹⁷ These meetings were often not open to the public or to mental health professionals. For instance, on August 9, 1977⁹⁸ the first psychiatric patient self-help group, the Ontario Mental Patients Association (later, in 1980, renamed On Our Own)⁹⁹ was established, consisting solely of individuals who were current or former patients of psychiatric hospitals. Through the creation of space for peer support¹⁰⁰ reflection and consciousness-raising about the experience of psychiatric treatments, the Ontario Mental Patients Association paved the way for the beginnings of a psychiatric ex-patient movement in Toronto. Reaume discusses the intricate narrative surrounding the Ontario Mental Patients Association's necessitated name alteration, shedding light on the complexities inherent in organizational nomenclature, identity construction, and the resultant tensions with governmental backing:

We started out in 1977 as the Ontario Mental Patients' Association (OMPA). We didn't like the name much ourselves—the words “mental patient” have a lot of negative connotations—and planned to change it at some point. We were pushed into changing it by the Government of Ontario when we applied for incorporation. The government was afraid we might be confused with the Mental Health Association, so we couldn't incorporate as OMPA. So we suggested the name Free Psychiatric Inmates. No, said the government. You're implying that people in psychiatric hospitals are prisoners, and that will never do. To speed up incorporation we adopted a name almost nobody liked, but

⁹⁷ Geoffrey Reaume “Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients' activism in North America” *Supra* note 15 at 416..

⁹⁸ Bob Pennington, “Psychiatric Patients to help themselves,” *Toronto Star* (1977). at D2.

⁹⁹ Geoffrey Reaume, Consumer Survivor Movement in Promoting Patients' Rights in Ontario 1977 to Present in Psychiatric Patient Advocate Office, *Mental Health and Patient Rights in Ontario: Yesterday, Today and Tomorrow* (Toronto: Queens Printer for Ontario, 2003) at 50.

¹⁰⁰ Peer support here refers to the way in which people with previous experiences in the psychiatric system would support one another (via friendship, talking, organising for change) in contrast to the contemporary professionalization and standardisation practices that are currently underway to certify “peer work”. For more information please see Peer Support Accreditation and Certification (Canada) <http://www.pfac-canada.com> [<https://perma.cc/PJ3G-SJRU>].

which was innocuous enough to please the government: the Ontario Patients ‘Self-Help Association (OPSHA).¹⁰¹

Terminology choices have the ability to impact those who use such terms¹⁰². In Canada the control over how service users identify has been an important component of the evolution of state medical support for personal choice, access to alternative viewpoints and ultimately to the potential of independent patient groups, a point I discuss later in chapter six.

Engagement in the many years prior can also be found in the history of The Toronto Psychiatric Survivors (TPS)¹⁰³ which emerged as the successor of an informal veterans group¹⁰⁴. In the late 1980s, TPS hired Kathryn Church to track participation in public hearings and legislative subcommittees¹⁰⁵ as part of a process to implement recommendations brought forward by the Graham Report.¹⁰⁶ The Graham report is often cited as the seminal report on mental health reform. While not arguing anything novel in terms of mental health reform, it did conceptually introduce the idea of “consumers and partnership” signalling that people with lived experience of mental health services had the capacity and skills that could augment any reform direction¹⁰⁷.

¹⁰¹ Geoffrey Reaume “Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients' activism in North America” *Supra* note 15 at 17.

¹⁰² David B Christmas, Angela Sweeney, “A. Service user, patient, survivor or client ... has the time come to return to ‘patient’? (2016) 209:1 *The British Journal of Psychiatry*.

¹⁰³ Kathryn Church, Beyond "Bad Manners": The Power Relations of "Consumer Participation" in Ontario's Community Mental Health System (1996) 15:2 *Canadian Journal of Community Mental Health* at 31.

¹⁰⁴ An email exchange with David Reville (former New Democratic member of the Legislative Assembly of Ontario from 1985 to 1990) clarified the history of the formation of the group Toronto Psychiatric Survivors. It was the successor to a veterans group that he and Pat Capponi organised. Email correspondence May 25, 2014.

¹⁰⁵ Kathryn Church led much of the research and subsequent consolidation of feedback by psychiatric survivors for the legislative committee involved in the work leading to the Graham report. These committees were the following: Ontario. The Legislative Sub-Committee of the Steering Committee on the Implementation of the Report of the Provincial Community Mental Health Committee. *Discussion paper towards community mental health services legislation*. (Toronto: Ministry of Health. 1990) as well as Ontario. The Implementation Strategy Sub-committee of the Steering Committee on the Implementation of the Report of the Provincial Community Mental Health Committee. *Fitting the pieces together: working document for 'Building Community Support For People; A Plan for Mental Health in Ontario'* (Toronto: Ministry of Health 1990).

¹⁰⁶ Robert Graham, *Building community support for people: A plan for mental health in Ontario*. (Toronto: Queen's printer, 1988).

¹⁰⁷ Kathryn Church. “Beyond ‘Bad Manners’ *Supra* note 103

Unlike the patient group, On Our Own, which operated independently from the state, TPS was one of the first organizations formed as an arm of the Consumer Survivor Development Initiative (CSDI). CSDI was born in response to take seriously the demand by mental health service agencies looking for individuals with mental health lived experience to participate on boards or advisory groups.¹⁰⁸ The convergence of mental health consumer/survivor social movement organizing and political pressure was part and parcel of this narrative context in which efforts at patient recognition and inclusion began to germinate through policy¹⁰⁹, conference gatherings¹¹⁰ and reports such as “*Do the Right Thing*”¹¹¹ and “*Building a Framework*”¹¹² alongside the migration of ideas from other jurisdictions¹¹³ to Canada. The narrative context was characterized by the confluence of mental health consumer/survivor social movement organizing and political pressures. Within this milieu, endeavours aimed at patient recognition and inclusion commenced to take root through various channels such as policy initiatives, conference assemblies, and seminal reports like "Do the Right Thing" and "Building a Framework." Concurrently, the migration of ideas from other jurisdictions to Canada further enriched this discourse, a topic which I will explore in the subsequent discussion.

¹⁰⁸ Barbara Everett, *A Fragile Revolution : Consumers and Psychiatric Survivors Confront the Power of the Mental Health System* (Waterloo: Wilfrid Laurier University Press, 2000) at 78.

¹⁰⁹ John Trainor, Bonnie Pape, Ed Pomeroy, *Building a framework for support, A community development approach to mental health policy* (Toronto: Canadian Mental Health Association, 1999) at 19-20.

¹¹⁰ Please see: John McKnight The Empowerment Conference in John Trainor, Bonnie Pape, Ed Pomeroy, *Building a framework for support, A community development approach to mental health policy. Ibid* at 131. Also see Jill Grant, “The Participation of Mental Health Service Users in Ontario, Canada: A Canadian Application of the Consumer Participation Questionnaire” (2007) 53:2 *International journal of social psychiatry*.

¹¹¹ Kathryn Church, David Reville. “Do the Right Thing Right.” (1990) 26 *Canadian Review of Social Policy*.

¹¹² John Trainor, Bonnie Pape, Ed Pomeroy, *Building a framework for support, A community development approach to mental health policy* *Supra* note 109.

¹¹³ Athena Helen Mclean, “From Ex-Patient Alternatives to Consumer Options: Consequences of Consumerism for Psychiatric Consumers and the Ex-Patient Movement.” (2000) 30: 4 *International Journal of Health Services*.

1.3 Patient Voice: Policy, Community 1960 - 2000

The 1960s onward constituted an era of change in mental health policy and services in psychiatry in Ontario.¹¹⁴ Here I describe key moments between the period of 1963 until 2000 to offer context on the efforts to build awareness of mental health as well as to implement patient groups as leaders in that change process. This holds significant importance as it bridges the historical advocacy efforts with contemporary endeavours. Grassroots movements, characterized by their "change from below" approach and their advocacy for human rights, frequently find themselves in conflict with the interests of influential entities or individuals lacking close ties to local communities or grassroots organizing. In other words, the imperatives articulated by advocates and activists often prioritize urgent, immediate concerns, including issues of survival, over the slower trajectory of systemic transformation within the mental health domain.¹¹⁵

To contextualize this history, I commence by examining the pivotal role of the Canadian Mental Health Association (CMHA), which boasts a rich legacy of spearheading mental health care strategies in Canada. The CMHA has wielded significant influence in shaping the advocacy agenda. The Ontario branch of the CMHA was founded in 1952 and for years, the CMHA's work consisted of submissions to the government or, initiatives aimed at raising awareness about the importance of mental health *as* a health issue.¹¹⁶ A decade later, the CMHA successfully created more awareness and strategies for political action, stemming from the successful uptake of their 1963 publication, "More for the Mind" which argued for better policy and health

¹¹⁴ Harvey G Simmons, *Unbalanced: Mental Health Policy in Ontario 1930-198*. (Toronto: Wall & Thompson 1990) at 87.

¹¹⁵ Examples of this today include the interminable challenges to for affordable housing, as well as the distinction between the advocacy of grass roots organizing for safe injection by activists creating infrastructures of care beyond the state. Please see: Fiona Jeffries *The right to safety in the city* (2019) Canadian Centre for Policy Alternatives. [<https://perma.cc/YJH7-HFJL>]

¹¹⁶ Canadian Mental Health Association, "History of the CMHA," Canadian Mental Health Association <https://toronto.cmha.ca/about-us/our-history> [<https://perma.cc/PAY5-G63S>].

legislation and more community clinics and smaller psychiatric hospitals.¹¹⁷ However, it was not until later in 1983 that the CMHA proposed and passed a national resolution¹¹⁸ which called for greater “consumer involvement” within its organization.¹¹⁸ It is not surprising that the CMHA passed such a resolution given the confluence of social movement organizing and political pressure that preceded it. This CMHA resolution was a suitable fit with a key notable shift in Ontario health care policy: the momentum gained during the work of the *Graham Report*.

Initiated in 1987 under the supervision of Robert Graham,¹¹⁹ the *Graham Report* endeavoured to develop a framework for the delivery of community mental health services. It strove for systemic changes that sought to develop better standards for programs (housing and vocational rehabilitation) as well as information and research about how to better serve women, youth, older adults and “Native groups.”¹²⁰ It was at this pivotal juncture that consumer/survivor representatives were invited to participate in 1989 in part, due to the advocacy of the Advocacy Resource Centre for the Handicapped (now ARCH Disability Law Centre)¹²¹ and the Psychiatric Patient Advocacy Office which would not agree to be the constituted voice for the consumer/survivor community.¹²² A respondent at the legislative committee consultation indicated that the initial exclusion of consumer/survivors was not an intentional omission, but rather due to it not being included in the “bureaucratic file drawer.”¹²³ The situation was

¹¹⁷ Steve Lurie, David Goldbloom, “More for the Mind and Its Legacy.” 2015 34:4 Canadian Journal of Community Mental Health at 7-30 <https://doi.org/10.7870/cjcmh-2015-007>.

¹¹⁸ Kathryn Church, David Reville. “Do the Right Thing Right” *Supra* note 111 at 2.

¹¹⁹ Robert Graham was appointed by Minister of Health Elinor Caplan to chair the Provincial Community Mental Health Committee which produced the report Building Community Support for People: A Plan for Mental Health in Ontario.

¹²⁰ Robert Graham, *Supra* note 106 at 1.

¹²¹ The Advocacy Resource Centre for the Handicapped is now called ARCH Disability Law Centre. The name was officially changed at ARCH’s Annual General Meeting on October 6, 2005.

¹²² Church, *Beyond Bad Manners Supra* at 36.

¹²³ Church, *Supra* note 103 at 32.

eventually remedied and the first psychiatric patient representative was given the green light to advocate for the interests of the patient voice. At the conclusion of the work of the legislative subcommittee for the Graham report, the steering committee on the implementation of the report remarked as follows:

With the best of intentions, the subcommittee embarked on its consultations but found a variety of problems and obstacles to meaningful involvement by consumer/survivors. As time went on, some of the difficulties being experienced were addressed, but not all. The consultation process was a powerful learning experience for subcommittee members, both in terms of people and process. The knowledge gained from the process will be extremely valuable in enabling the Ministry of Health to “do it right” in future consultations.¹²⁴

The desire to “do it right” prompted a brief aptly entitled, *Do the Right Thing*, authored by David Reville during his tenure as a member of the provincial legislature. *Do the Right Thing*, analysed mental health service legislation consultations by the Ontario Ministry of Health and offered recommendations as well as information on experiences of participation by consumer/survivors as demonstrated in this reflection about the role of Toronto Psychiatric Survivors (TPS):¹²⁵

The emergence of TPS was closely related to the policy shift in the government bureaucracy which has helped to make “consumer participation” the hottest word in the new mental health lexicon. Survivor activists recognized both the opportunities and dangers in service-provider interest in consumer representation on organizational boards.¹²⁶

In re-reading the brief, it becomes evident that issues concerning credibility, identity, representation, and legitimacy, which have historically emerged, persist as salient themes in contemporary discussions surrounding inclusivity. There is an ever-growing literature discussing the ways in which inclusion and involvement are fraught with convolutions and more questions

¹²⁴ Church, *Supra* note 103 at 34.

¹²⁵ Church and Reville *Supra* note 111 at 2.

¹²⁶ Church and Reville *Supra* note 111 at 8.

about what one means by “engagement.”¹²⁷ However, in the ‘70s and ‘80s, the concept of including individuals who were current or former patients in the mental health system was “new”, and as such, must be differentiated from the present calls for patient engagement. Until 1985, patients in psychiatric hospitals were not afforded the right to participate in elections, a restriction indicative of the prevailing opposition to extending such voting privileges to them.¹²⁸ Hence, prior endeavours aimed at incorporating and engaging mental health care consumers cannot be divorced from the custodial and paternalistic milieu characteristic of psychiatric medicine, prevalent from the 1970s through to the 1990s. Effecting change necessitated a multifaceted shift encompassing attitudes, policies, and resource allocations. A depiction of some of these transformative processes is encapsulated in the 1999 publication, *Building a Framework*, published with the intent of synthesising the previous seventeen years of mental health care policy development, and implementation in Ontario.¹²⁹

1.4 Building a Framework

The "Building a Framework" initiative developed a "framework model" aimed at integrating consumer/survivors and families into mental health treatment, anchored on three key thematic pillars: transformation and change, respect and recognition, and partnership..¹³⁰ In a chapter entitled, “Participating,” the authors describe the “principles for action” that should guide legislative and policy changes in the provision of mental health care, and note the instrumental

¹²⁷ Please see: Paula Rowland and Arno K. Kumagai, "Dilemmas of representation: patient engagement in health professions education." (2018) 93:6 Academic Medicine.

¹²⁸ See: CBC, Lifting voting restrictions on the mentally ill. CBC. (November 16, 1988) <https://www.cbc.ca/archives/entry/lifting-voting-restrictions-on-mental-patients> [https://perma.cc/NS9H-3GQ7]

¹²⁹ John Trainor, Bonnie Pape, Ed Pomeroy, *Building a framework for support, A community development approach to mental health policy* Supra note 109.

¹³⁰ *Ibid* at 19.

role of “self-help groups” and consumer groups in giving consumers of mental health care a sense of agency.¹³¹ As a text, this book has some utility in synthesizing some of the history that pushed for patient inclusion in matters of mental health care irrespective of the advancements that were already happening in the nineties. Consumer/survivors and their allies worked more deliberately with public policy actors towards inclusion in mental health system transformation, often invoking the argument for a “seat at the table”¹³² in order to initiate a more direct call for engagement with structures of power and authority such as the Ministry of Health, which had not previously included the voices and perspectives of consumer/survivors.

In a subsequent essay published in 2002, Trainor, Pape, and Pomeroy reiterated the arguments articulated in "Building a Framework" and reaffirmed the notion that the future trajectory of mental health care policy should not be entrenched within rigid formal systems.¹³³ Instead, they advocated for a shift towards fostering partnerships with service users and families, highlighting the efficacy of such collaborations in providing optimal support for individuals struggling with mental health challenges. The essay revisits the Empowerment Conference of 1985, emphasizing the inception of the "User Involvement Task Group." This group played a pivotal role in shaping the establishment and structure of the Canadian mental health consumer advisory council. Notably, the council succeeded in facilitating the election of consumers to the organization's Board and, in 1989, appointed a consumer/survivor staff member tasked with spearheading the development of a national advisory network spanning the entirety of Canada.

¹³¹ *Ibid* at 101-102.

¹³² William Boyce et al. *A seat at the table: persons with disabilities and policy making* (Montreal: McGill-Queen's University Press, 2001).

¹³³ John Trainor, Bonnie Pape, Ed Pomeroy “Citizens Shaping Policy: The Canadian Mental Health Association’s Framework for Support Project” (2002) February: 43:1 *Canadian Psychology* at 11-20.

The National Network of Mental Health (NNMH) was incorporated in October 1991, and in 1995, held its founding conference, “United We Stand,” managing a \$1.5 million dollar budget.¹³⁴ Over the years, the NNMH had a considerably reduced budget¹³⁵ and at the time of writing this thesis, it appears to no longer have an active website or operating structure. Instead, a professionally driven organization holds that role; the Mental Health Commission of Canada, funded by Health Canada, acts as a leading organization for mental health and addiction issues nationally¹³⁶. While there may be some service user/survivors working within the structure of the Mental Health Commission of Canada, there is no single identifiable advisory body or committee solely made up of service users/survivors.

While the NNMH was incorporated in 1991, in Ontario, the first provincially sponsored consumer/survivor initiative was born a few months prior, in the spring of 1991.¹³⁷ The Consumer Survivor Development Initiative (CSDI) was funded by the Ontario Ministry of Health and Long-Term Care in order to assist with the development of employment support and opportunities within the wider consumer /survivor community in order to enable service users to develop initiatives that “help people, help themselves.”¹³⁸ When first formed in 1991, CSDI had six staff members, only three of whom were service users. By 1992, they developed 42 programs across Ontario and created employment opportunities for consumers/survivors, helping many transition from social assistance to employment. By 1993, the CSDI became fully operational

¹³⁴ *Ibid* at 16.

¹³⁵ The National Network for Mental Health, *Statement of Revenue Expenses and Net Assets Year end March 31, 2013* The National Network for Mental Health <http://nnmh.ca/who-we-are/agm>. [<https://perma.cc/G94X-9AD5>]

¹³⁶ Mental Health Commission of Canada. mentalhealthcommission.ca/about

¹³⁷ John Trainor et al. “Beyond the Service Paradigm: The Impact and Implications of Consumer/Survivor Initiatives” (1997) 21: 2 *Psychiatric Rehabilitation Journal*.

¹³⁸ Government of Ontario, *Putting people first: The reform of mental health services in Ontario*. (Toronto: Government of Ontario Publication, 1993) at 7.

with consumer/survivors at the helm and a \$3.1 million budget.¹³⁹ In 2001, the CSDI formed its first board of directors out of an advisory committee and changed its name to the Ontario Peer Development Initiative (OPDI) to reflect the changing climate in the mental health sector and a growing focus on the discourse of “peers.” The OPDI again changed its name to “Peer Works” in 2022 and has 43 affiliated member organizations listed on its website.¹⁴⁰ Current Peer Works membership is a grouping both of organizations that are governed by service users/survivors and of organizations that are not, but are more traditional mental health care agencies such as the CMHA.⁴³

The shifting landscape of advocacy in Canada and Ontario can be delineated to the year 2006, which is marked by systematic reductions in funding by the federal government to organizations championing progressive public policies. This included cuts to funding for initiatives such as the Court Challenges Program, Status of Women in Canada, Indian Nation, and the Canadian Council for Refugees.¹⁴¹ In Ontario, it is important to also acknowledge the notable decline of independent consumer/survivor organizations and initiatives during this period. Beginning in the early 1990s and continuing thereafter, a series of Consumer/Survivor Initiatives (CSIs) emerged across the province. These initiatives were established and operated exclusively by individuals who had personally experienced mental health challenges. Historically, these CSIs had offered peer support, education and training both for the public and for mental health care professionals, individual and systemic advocacy skills development, and the creation and distribution of consumer/survivor-based knowledge, arts and cultural

¹³⁹ *Ibid* at 133.

¹⁴⁰ Peer Works online: <<https://www.peerworks.ca> > [<https://perma.cc/3X5R-9MD4>]

¹⁴¹ Gloria C Desantis, and Nick J. Mulé. “Advocacy: a contested yet enduring concept in the Canadian landscape. In Gloria c. Desantis and Nick J Mulé ds. *Shifting terrain: nonprofit policy Advocacy in Canada*, (McGill-Queen’s University Press, 2017) at 3–32.

activities.¹⁴² In the last decade-and-a-half, many of these organizations have lost their funding or, have been amalgamated within larger mental health organizations, such as the CMHA. These changes can be attributed to the economic deficit of the mid-nineties and to the rise of New Public Management, which continues today and has curbed funding to many non-profit organizations.¹⁴³ Yet, new discourses on the value of patient engagement and client-centred approaches to mental health care have emerged, aimed at improving mental health care services despite budgetary challenges. As independent consumer/survivor initiatives waned, there may have been a corresponding increase in hospital-led efforts to engage patients. This shift reflects a change in the dynamics of patient involvement in mental health care, with a potential transition from grassroots, community-driven initiatives to more institutionally driven endeavours. In contrast, today, Peer Works persistently advocates for increased budget allocations. In 1991, it operated with a budget of just over \$3 million annually, today, it operates with only \$300,000 per year, representing a funding reduction of over 900% during that period. This drastic decrease in funding has resulted in the closure of multiple CSIs, particularly in critical regions where their absence has been keenly felt.¹⁴⁴

1.5 Patient Government, Councils, and Human Rights

This study examines the trajectory of independent governance in service user organizations, such as CSIs, and their political power. By doing so, it aims to deepen our understanding of past engagement efforts and contribute to the ongoing scholarship on inclusion and deliberative

¹⁴² Geoff Nelson, Joanna Ochocka, Rich Janzen and John Trainor, “A longitudinal study of mental health consumer/survivor initiatives: Part 1 (2006) May: 34: 3 *Journal of Community Psychology* at 247.

¹⁴³ Desantis, and Mulé. *Supra note 140*.

¹⁴⁴ Allyson Theodorou, Online:

“<https://www.peerworks.ca/uploads/PeerWorks%20Budget%20Request%202022:2023.pdf>”
<https://perma.cc/KM5D-6HWY>).

democracy in psychiatry. Evaluating the effectiveness of these initiatives requires contextualizing them within the broader literature, particularly when considering their relationship to the pursuit of justice and human rights for mental health patients. Before the ECFAA,¹⁴⁵ the drive to include patients in hospital practices began in the 1960s and remains a recurring trend in healthcare today. The establishment of Patient Councils in Ontario is a central element of this ongoing narrative.

Although not widely recognized, there was a period during which models of "patient government" surfaced within hospital settings prior to contemporary understanding. Patients were the focus of a prevalent treatment model rooted in psychological theories emphasizing power-sharing and institutional democratization, influenced by the "therapeutic community" concept (later termed "patient government", or "patient councils")¹⁴⁶ initiated by Maxwell Jones post-World War II.¹⁴⁷ This transition away from paternalistic attitudes associated with total institutions now aimed towards perspectives that prioritized patient autonomy and self-determination.¹⁴⁸ In hospitals, inclusive projects sought input from various stakeholders, including patients, staff, and doctors, while therapeutic patient government models were established. The emphasis also extended to instilling a sense of responsibility by empowering patients to participate in committee work and the organization of hospital activities, with the intention of fostering their role as active contributors to the hospital community:

¹⁴⁵ *Excellent Care for All Act*, *Supra* note 1.

¹⁴⁶ Therapeutic community first emerged as a means to support psychiatrists and war veterans grappling with war-time trauma. Its objective was to "normalize" patients for swift reintegration into the community. Key features of the model included democratic decision-making processes, shared responsibilities, and group therapy sessions. Patients actively participated in the day-to-day operations of the community, undertaking chores, activities, and therapeutic interventions guided by psychological theories emphasizing power-sharing, therapeutic community dynamics, and institutional democratization.

¹⁴⁷ Maxwell Jones, *The Therapeutic Community: A New Treatment Method in Psychiatry* (New York: Basic Books, 1953).

¹⁴⁸ Mary Seeman, Forty-five years of schizophrenia: personal reflections (2006) 17 *History of Psychiatry*. at 364.

He cannot wait passively for treatment to be administered to him. He must be active in his own treatment using the resources of the community to explore his problems, to our new attitudes and behaviour and rebuild his personality. In addition, he must assume his share of responsibility for the function of the community and the treatment welfare of his fellow patients.¹⁴⁹

In the fabric of this approach was an assumption that by facilitating such participation, the hospital environment mirrored that of the outside world; that it could seamlessly reflect the world beyond its walls and subsequently prepare patients for reintegration into that world.¹⁵⁰ A 1959 excerpt from the minutes of a patient meeting (at the Ontario Hospital, now CAMH) serves as an illustrative example, encapsulating the particular concern raised within the carceral context of such “patient government” deliberations:

Many of us feel that more doors can be opened here. With the closed door, it is locking people up, and sometimes makes things a lot worse and that even someone who appears very sick has unusual assets and capabilities, much more than people think. Those who work in hospitals know how much trouble people have, and locking them up with bars is the worst thing¹⁵¹

The therapeutic community/patient government model ended due to healthcare policies, criticisms, and the deinstitutionalization movement pushing community-based care. Deaths linked to the model at the Ontario Hospital (now CAMH) prompted scrutiny and calls for an independent inquiry. By 1982, Peat Marwick and Partners¹⁵² had assessed the situation, issuing a report containing 62 recommendations. This report influenced the hospitals’ direction, driving a move towards a more specialized service delivery model, particularly through centralizing

¹⁴⁹ A. W Clark. “Patient Participation and Improvement in a Therapeutic Community.” (1967) 20:3 Human relations.

¹⁵⁰ LA Ravsten, “Leadership training for patient government” (1969) Oct 20:10 Hospital Community Psychiatry. 317-20.

¹⁵¹ CAMH Archives, Meeting Minutes of Hospital Ward Council Ontario Hospital, Toronto (CAMH Archives, Minutes January 21, 1959).

¹⁵² Now known as KPMG. Peat Marwick merged with Klynveld Main Goerdeler (KMG) in 1987 to form KPMG.

administrative functions.¹⁵³ In the trajectory of this model's rise and fall, a most stark example of its reported exploitation and abuse resides in the civil lawsuit filed by 28 former patients of the Oak Ridge Division of the Penetanguishene Mental Health Centre (now known as Waypoint Centre for Mental Health Care) against the government of Ontario and two psychiatrists for subjecting them to coercive, unethical and degrading human experimentation, from 1966 to 1983 and which encompassed aspects of the therapeutic community's model.¹⁵⁴

As such, for the most part, psychiatric hospitals throughout the eighties were uninterested in patient groups or advocating for their inclusion into the nature of those treatments. Following the election of the New Democratic Party (NDP) in September 1990, the establishment of the Advocacy Commission ensued, accompanied by renewed vigour for rights reform and advocacy,¹⁵⁵ epitomized by the NDP's Ontario *Advocacy Act*.¹⁵⁶ Shortly thereafter, Patient Councils re-emerged as pilot project within hospitals beginning first at Kingston and second at Queen Street hospital, (now CAMH).¹⁵⁷ While the focus of this thesis does not centre on the advocacy and history of patient councils in this era, it is important to note their relevance. These councils were driven by patients (as opposed to hospital agendas) and were established with the aim of amplifying the voices and rights of service users/survivors and ensuring their

¹⁵³ Peat Marwick & Partners, "Queen Street Mental Health Centre: report and organizational review by Peat Marwick and Partners." (Toronto: Department of Public Health, 1982) at 9.

¹⁵⁴ *Barker v. Barker*, 2020 ONSC 3746.

¹⁵⁵ William Boyce and Mary Ann McColl, Initial. "The Ontario Advocacy Act: Representing persons with intellectual disabilities." In William Boyce et al, *A seat at the table: Persons with intellectual disabilities and policy making* (Montreal: McGill-Queens University Press, 2001) at 85-91.

¹⁵⁶ *Advocacy Act*, 1992 [REPEALED], SO 1992, c 26, Repealed.

¹⁵⁷ Theresa Claxton, "From Oppression to Hope: Advocacy Voice and Choice. The History of the Patient Councils and the Ontario Association of Patient Councils in Ontario-Yesterday, Today and Tomorrow" in *Honouring the Past, Shaping the Future. Psychiatric Patient Advocate office 25th Anniversary Report*. (Toronto: Queens Printer for Ontario 2008).

representation as equal partners across all levels of mental health service provision and advocacy.¹⁵⁸

1.6 From Degeneracy to Civic Patienthood: Recovery Discourse

In the early 2000s, the literature on “mental health recovery” slowly made its way into the mental health sector, and what followed was a major shift in the way the system thought, and spoke about patient care. The “recovery movement” began in the United States, building on the work of consumer/survivors, and was further aided by empirical studies¹⁵⁹ which demonstrated that patients could and do get better over time—a welcome message and a change from the routine assumption that patients would be sick for the rest of their lives. This time period exemplified how patients who were at the mercy of a custodial system were now able to recover, speak for themselves, and become active participants in both their treatment and hospital discourse. Patient groups and patient councils also became engaged in the promotion of the recovery model, recognizing its potential as empirical leverage for human rights advocacy and liberation from oppressive aspects of the mental health. However, as the model found its place within the mental health sector, intertwining itself with the agendas of the Ministry of Health, its appeal waned.¹⁶⁰ The concept of recovery no longer challenged the prevailing push for normalcy

¹⁵⁸ *Ibid.*

¹⁵⁹ For more background on empirical studies on mental health recovery please see: Mike Slade, & Eleanor Longden. “Empirical evidence about recovery and mental health” (2015). *BMC Psychiatry*, 15(1), 285; Larry Davidson, “The Recovery Movement: Implications For Mental Health Care And Enabling People To Participate Fully In Life.” (2016) 35:6 *Health Affairs* and Courtney Harding, et al. “The Vermont longitudinal study of persons with severe mental illness II: long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia”. 1987 *American Journal of Psychiatry*.

¹⁶⁰ Jennifer Poole, *Behind the Rhetoric: Mental Health Recovery in Ontario* (Halifax: Fernwood Pub., 2011) at 15.

within psychiatry; instead, it transformed into an emphasis on "recovery" as a path towards rehabilitation and cure, overshadowing concerns about rights issues.¹⁶¹

The recovery paradigm received significant validation from several noteworthy clinical investigations. One such study, conducted by Courtney Harding, involved a longitudinal examination of patients diagnosed with schizophrenia who were previously confined to the "backwards" of Vermont State Hospital during the late 1950s and early 1960s.¹⁶² The study monitored the progress of a cohort of patients discharged from the hospital over a span of 32 years. Following their release, the patients received a combination of social support, participation in a rehabilitation program, and limited medication use. This approach resulted in significantly improved outcomes compared to previous understandings within the psychiatric field; twenty years later, 25% to 50% of the patients had achieved complete recovery, often without medication.¹⁶³ Loren Mosher's work made similar findings in his randomized Soteria House study.¹⁶⁴ Operational from 1971 to 1983, Soteria House implemented a community-based therapeutic approach without coercion, contrasting with conventional psychiatric interventions. Research found that individuals from Soteria House showed improved long-term outcomes (i.e. fewer hospitalisations, were able to hold down jobs, were living independently or with peers), often without medication.¹⁶⁵ This emphasis on recovery fostered hope within psychiatric care and influenced clinical practice.

¹⁶¹ *Ibid*

¹⁶² C. M. Harding et al. "The Vermont longitudinal study of persons with severe mental illness: II Long-term outcome of subjects who retrospectively met DSM-II criteria for schizophrenia" (1986) 144 *American Journal of Psychiatry* at 727-735.

¹⁶³ *Ibid*.

¹⁶⁴ Loren Mosher, "Soteria and Other Alternatives to Acute Psychiatric Hospitalization: A Personal and Professional Review" (1999) 187:3 *The Journal of Nervous and Mental Disease* at 142-149.

¹⁶⁵ Loren Mosher, Alma Menn, Susan Matthews, Soteria: Evaluation of a home-based treatment for schizophrenia (1975) 45:3 *American Journal of Orthopsychiatry* at 455-467.

Over the course of two decades, the recovery framework has undergone a transformative shift in Ontario. Initially met with scepticism regarding its feasibility for patients, by the year 2000, the recovery framework had gained significant traction. Funding for initiatives began to materialize, and gradually, the principles of recovery permeated various aspects of the mental health landscape, manifesting in training sessions, posters, research proposals, and health informatics and metrics technology¹⁶⁶. Hospitals initiated the establishment and employment of "recovery facilitators," eventually incorporating peer workers as integral contributors to advancing recovery initiatives and fostering comprehensive care for psychiatric patients. The additional challenges with mental health recovery, as Morrow points out, are that "particular understandings of recovery have come to predominate" and have reproduced individualistic frames that do not address wider and more complex analyses of the social structures and power relations that exist in mental health.¹⁶⁷

Previously met with resistance as a conceptual framework, the notion of "recovery" evolved into an avenue for fostering novel discourses concerning collaboration between patients and clinicians, rapport development, and co-production within client medical records, including facilitation by technological metrics.¹⁶⁸ In the tapestry of healthcare, certain patient units emerged under the banner of "mental health recovery units."¹⁶⁹ Gone are the days when patients

¹⁶⁶ Please see: Kristi-Ann Villagonzalo, Nuwan Leitan, John Farhall, Fiona Foley, Bronte McLeod, Neil Thomas, "Development and validation of a scale for self-efficacy for personal recovery in persisting mental illness" (2018) 269 *Psychiatry Research*.

¹⁶⁷ Marina Morrow, "Recovery: Progressive paradigm or neoliberal smokescreen" in Brenda LeFrancois, Robert Menzies, Geoffrey Reaume, (eds.), *Mad matters: A critical reader in Canadian mad studies* (Toronto: Canadian Scholars' Press, 2013) at 323 – 333.

¹⁶⁸ Deede Gammon, Monica Strand, Lillian Sofie Eng, Elin Børøsund, Cecilie Varsi, and Cornelia Ruland, "Shifting Practices Toward Recovery-Oriented Care Through an E-Recovery Portal in Community Mental Health Care: A Mixed-Methods Exploratory Study." (2017) 19:5 *J Med Internet Research*.

¹⁶⁹ For example, please see: Canadian Union of Public Employees and its Local 942 v Royal Ottawa Health Care Group – Royal Ottawa Mental Health Centre, 2024 CanLII 53387 (ON LA) <https://canlii.ca/t/k56f7> at para 96, 110.

were viewed as degenerate, societal outcasts, relegated to the margins of care. Instead, patients now stand as respected active architects of their own well-being, shaping their paths towards healing and recovery.¹⁷⁰ Their contributions to self-care are not merely abstract notions but tangible actions, “measurable” in their impact and significance. The existing recovery literature and recovery practice however, are devoid of significant linkages to human rights processes, remedies or complexities. Given the numerous individuals with mental health issues who, in fact, do find themselves bound up in legal problems in a variety of tribunals or courts,¹⁷¹ it is important to question how “recovery” could or should interface with law (particularly in carceral environments).¹⁷² There are growing analyses and critiques of the limitations of recovery frameworks and their implications for citizenship, particularly in light of the rise of neoliberal logics, which favour welfare state retrenchment and increased managerialism.¹⁷³

The problem with the ways in which “recovery” evolved is best described by Morrow in response to the deinstitutionalisation process that occurred with the Vancouver Riverview Hospital in British Columbia in 2012. The lack of subsequent support or community resources for released patients inevitably exacerbated their challenges with poverty, substance use and homelessness when they returned to life outside the hospital. Where once patients were living in psychiatric units, recovery catapulted policy to argue that it was important to discharge patients and support them with their recovery and independent living. Morrow states,

¹⁷⁰ David Pilgrim, “Recovery From Mental Health Problems: Scratching The Surface Without Ethnography.” (2009) 23:4 *Journal of social work practice* at 477.

¹⁷¹ Please see: Legal Aid Ontario, “Mental Health Strategy Consultation Paper” online: <https://www.legalaid.on.ca/wp-content/uploads/Mental-Health-Strategy-for-Legal-Aid-Ontario-EN.pdf> [https://perma.cc/5SL2-6453].

¹⁷² Liam Kennedy, Joshua D. M. Shaw, and Tyler J. King. “Disciplinary Paternalism and Resistance in Ontario’s Forensic Mental Health System.” (2023) 31:3 *Critical criminology* at 843.

¹⁷³ Julia Weisser, Brenda Jamer, and Marina Morrow. *A Critical Exploration of Social Inequities in the Mental Health Recovery Literature*. Vancouver, B.C: Centre for the Study of Gender, Social Inequities and Mental Health, Simon Fraser University 2012.

[t]he “healthification” of social problems fits neatly into the agenda of neoliberalism with the implications for the ways in which the concept of recovery is poised to be taken up as an individual journey requiring the “manpower” of the individual to create a healing environment, and his or her family and social support network to provide the engine of hope, devoid of any analysis of the social context in which mental distress occurs and is managed.¹⁷⁴

The “healthification” as Morrow calls it substantiates the ways in which recovery has been a flexible term that can be adopted and used in ways that have benefited the state at the expense of the service user. As institutions adopted facets of recovery, service users were left wondering how “recovery” could improve their quality of life, arguing that recovery has become a “crutch” health care workers lean on instead of “doing their job”.¹⁷⁵

Throughout much of the period spanning 2000-2020, the ascendancy of recovery frameworks has eclipsed other paradigms and concerns among service users, including human rights, disability rights, and efforts against racism, sexism, and homophobia. While recovery features prominently in some of the PDoVs I examined (for example, Waypoint, calls its PDoV a *Declaration of Recovery Values*)¹⁷⁶ its prevalence within hospital discourse persists, albeit subject to varying interpretations. Perhaps for some, the recovery model has been helpful while for others it is perceived as coercive, particularly in instances where patients are compelled to undergo treatments such as medication regimens or electro-convulsive therapy (ECT) in the name of recovery.¹⁷⁷

¹⁷⁴ Morrow *Supra* note 166 at 327-329.

¹⁷⁵ Mental Health “Recovery” Study Working Group, “Mental Health “Recovery”: Users and Refusers.” (January 2009) online: https://www.wellesleyinstitute.com/wp-content/uploads/2011/11/Mental_Health- Recovery.pdf at 31.

¹⁷⁶ Waypoint Centre for Mental Health Care (Penetanguishene), “Declaration of Recovery Values” online: https://cdns5-hosted.civiclive.com/UserFiles/Servers/Server_9960/File/Declaration%20of%20Recovery%20Values/Declaration_of_Recovery_Values.pdf [https://perma.cc/6SYQ-ALJ2]

¹⁷⁷ *Ibid* at 31.

1.7 The New Panopticon: Patient Engagement

The literature on patient engagement is now enormous, but prior to the advent of patient engagement, clinicians often grappled with the challenge of patient *disengagement* in psychiatric treatment.¹⁷⁸ As the trajectory of patient engagement discourse has exploded, its narrative has expanded to embrace collaborative partnership models alongside the customary consultation roles which endeavour to position patients shoulder to shoulder with healthcare professionals, researchers, managers, and policymakers - patients assume diverse identities, ranging from patient partners to patient advisors, echoing the evolving dynamics of this profound interaction.¹⁷⁹ Institutions adeptly, and perhaps inadvertently, orchestrate tailored modes of engagement, favouring those that harmonize with their objectives, while concurrently relegating dissenting viewpoints to the margins. This section offers a brief discussion of patient engagement, explaining its scope within the expansive research domain.

Incorporating the perspective of patient representatives into health services has roots in the early social movement efforts of psychiatric patients¹⁸⁰ and in law.¹⁸¹ Additionally, it finds resonance in the advocacy of the disability movement, which revitalized the mantra "Nothing about us, without us" in the 1990s.¹⁸² More recently, in the last two decades, the LGBTQ2S communities have put pressure on health care policy to be aware of issues affecting

¹⁷⁸ Julie Kreyenbuhl, Ilana R. Nossel, Lisa B. Dixon, "Disengagement From Mental Health Treatment Among Individuals With Schizophrenia and Strategies for Facilitating Connections to Care: A Review of the Literature," (2009) 35: 4:4 *Schizophrenia Bulletin*.

¹⁷⁹ Meredith Vanstone, M., Carolyn Canfield, et al. "Towards conceptualizing patients as partners in health systems: a systematic review and descriptive synthesis." (2023) 21:12 *Health Res Policy Sys*.

¹⁸⁰ Church and Reville *Supra* note 111.

¹⁸¹ For a detailed account of the principles guiding robust patient advocacy and consent to treatment, please see: Bernard Dickens, "Medical consent legislation in Ontario" (Autumn 1994) 2:3 *Medical Law Review*.

¹⁸² James Charlton, *Nothing About Us Without Us Disability Oppression and Empowerment*. (Berkeley University of California Press: 1998) at 3-20.

members of this community.¹⁸³ For instance, the Trans community has argued for better inclusion and analysis of the experiences of Trans people in health care¹⁸⁴. In the early nineties, the breast cancer activist movement helped to redefine breast cancer as a major health policy issue in need of better governmental action.¹⁸⁵ Although Canada has formulated its own methodologies regarding patient engagement, it leveraged the experiences and model of the United Kingdom and the United States¹⁸⁶. In the UK, the NHS led patient participation initiatives such as INVOLVE since the mid-nineties, promoting engagement in research. In 1996, INVOLVE emerged from the NHS Research and Development Programme's Standing Advisory Group on Consumer Involvement, releasing guidelines for health researchers in 2000. However, in April 2020, INVOLVE merged with the NIHR Dissemination Centre, with the contract awarded a multinational private company specializing in the life sciences.¹⁸⁷

In the United States, the Patient-Centred Outcomes Research Institute (PCORI) was established by the *Patient Protection and Affordable Care Act* of 2010 to fund and encourage inclusive and effective research.¹⁸⁸ While PCORI has rallied patients and researchers, concerns persist about the depth of patient involvement, limiting its impact. This sporadic support raises questions about PCORI's effectiveness, leaving it vulnerable to criticisms of ineffectiveness due to a lack of transformative findings. According to one study, patient participants in PCORI felt

¹⁸³ Nick J. Mulé, et al. "Promoting LGBT health and wellbeing through inclusive policy development" (2009) 8 *Int J Equity Health* at 18.

¹⁸⁴ Please see: Dan Irving & Rupert Raj. *Trans Activism in Canada: A Reader*. (Toronto: Canadian Scholars: 2014) and Merrick Pilling. *Queer and Trans Madness: Struggles for Social Justice*. (Palgrave MacMillan: 2022).

¹⁸⁵ Emily S. Kolker, "Framing as a Cultural Resource in Health Social Movements: Funding Activism and the Breast Cancer Movement in the US 1990–1993." (2004) 26:6 *Sociology of health & illness* 820–844.

¹⁸⁶ Julia Abelson and John. Eyles. *Public Participation and Citizen Governance in the Canadian Health System*. (Ottawa: Commission on the Future of Health Care in Canada, 2002) at 20.

¹⁸⁷ Sarah Carr and Jonathan Boote. "Is Patient and Public Involvement Being Privatised?" 366 (2019) *BMJ*.

¹⁸⁸ JAMA and Archives Journals, "Need for greater patient and clinician involvement in comparative clinical effectiveness research (2012, April 17), online: <https://medicalxpress.com/news/2012-04-greaterpatient-clinician-involvement-clinical.html>.

they were superficially supporting PCORI's mission rather than redirecting its practices.¹⁸⁹ In the realm of research, service users, despite their involvement, continue to experience barriers, hindering their access to valuable opportunities.¹⁹⁰

In Canada, as the domain of Mad Studies expands, paradoxically, autonomous service user organizations lose their funding and cultural capital¹⁹¹ and power. Instead, governmental funding bodies and healthcare institutions have eagerly adopted policies promoting engagement, championing methods of "participatory" research and the like. However, this shift has birthed a peculiar type of "engagement creep."¹⁹² This "creeping" trend sees groups or individuals gradually absorbed into research endeavours, eroding the community's ability to genuinely steer its own research agenda. This erosion is especially pronounced when compounded by the weariness and harms¹⁹³ of repeated research participation experienced by these very communities and its participants¹⁹⁴ as well as the ethical challenges of "recruitmentology".¹⁹⁵

¹⁸⁹ Ann C Keller, et al. "Impossible Politics? PCORI and the Search for Publicly Funded Comparative Effectiveness Research in the United States," *Journal of health politics, policy and law* (2019) 44:2 at 221–265.

¹⁹⁰ Nev Jones, , Linda Callejas, Marie Brown, Michelle Colder Carras, Bevin Croft, Shannon Pagdon, Lindsay Sheehan, Oladunni Oluwoye, and Yaara Zisman-Ilani. "Barriers to meaningful participatory mental health services research and priority next steps: findings from a national survey. (2023) 74: 9 *Psychiatric Services*.

¹⁹¹ Here, I draw upon Pierre Bourdieu's definition of "cultural capital," which refers to the cultural assets possessed by groups, including knowledge, skills, and education. These assets can confer social advantages and contribute to social mobility. Please see: Pierre Bourdieu,. "Distinction a social critique of the judgement of taste." (Cambridge: Harvard University Press, 1984).

¹⁹² Fern Brunger and Darlene Wall, 'What Do They Really Mean by Partnerships?' Questioning the Unquestionable Good in Ethics Guidelines Promoting Community Engagement in Indigenous Health Research." (2016) 26: 13 *Qualitative Health Research* at 1872.

¹⁹³ For discussion of harms in participatory research please also see: Lori Ross, Merrick Pilling, Kendra Ann Pitt, and Jijian Voronka. "Even with the Best of Intentions. An Accounting of Failures in a Participatory Research Project" in Claire Carter, Chelsea Temple Jones, Caitlin Janzen (Eds) *Contemporary Vulnerabilities: Reflections on Social Justice Methodologies* (The University of Alberta Press, 2024).

¹⁹⁴ Bunger and Wall *Supra* note 192.

¹⁹⁵ Recruitmentology addresses questions pertaining to the methods and strategies used to recruit and retain participants in research studies, particularly those from underrepresented or "hard-to-recruit" populations. It involves evaluating various social, cultural, psychological, technological, and economic approaches to effectively persuade individuals to participate in and remain part of research projects. Please see: Steven Epstein,. "The Rise of 'Recruitmentology': Clinical Research, Racial Knowledge, and the Politics of Inclusion and Difference." (2008) 38:5 *Social Studies of Science*.

Prior to the literature on psychiatric patient engagement or user involvement, the disability movement had carved out an emancipatory research agenda, building from the feminist and civil rights movement¹⁹⁶. In the realm of service user/survivor literature, a significant challenge pertains to recognizing the epistemology of service users/survivors, a perspective historically marginalized. This relegation perpetuates the perception that psychiatric patients serve merely as objects rather than as agentive contributors of psychiatric research.¹⁹⁷ Additionally, mental health research heavily relies on the labour of contract researchers, many of whom operate under precarious and exploitative contracts.¹⁹⁸ User-led research is often perceived as less valid¹⁹⁹ than traditional psychiatric research and faces challenges in securing funding in many jurisdictions.²⁰⁰ Diana Rose, a professor in the field of service user-led research, has expressed concerns about the future prospects of this type of research and contends that service user research is not a passing trend; rather, it holds credibility and offers benefits to

¹⁹⁶ Please see: Lisa Vanhala, “Twenty-Five Years of Disability Equality? Interpreting Disability Rights in the Supreme Court of Canada.” (2010) 39.1 *Common law world review* 27–47; Brenda Brueggemann et al. “What Her Body Taught (Or, Teaching About and with a Disability): A Conversation.” (2005) 31:1 *Feminist studies* 13–33 and Catherine Kudlick “Disability History: Why We Need Another ‘Other’” (2003) 108:3 *The American historical review* 763–793.

¹⁹⁷ One such example was an notable open letter to *Lancet Psychiatry's* Editorial Office dated December 6th, 2019, with both commendation and critique for their innovative service user journal review initiative. While applauding the initiative's progressive direction in recognizing the importance of including service users, concerns were raised by over 50 professors and several organizations regarding *Lancet's* communication. Specifically, the letter highlighted the lack of emphasis on prioritizing user/survivor researchers, the choice to partner with a non-user-led organization, and the criteria for selecting service user reviewers. The letter advocated for a more inclusive approach that integrates individuals with lived experience and research expertise into the review process, emphasizing the significance of supporting user/survivor researchers in mental health research.

¹⁹⁸ Stan C Papoulias and Felicity Callard. "Material and epistemic precarity: It's time to talk about labour exploitation in mental health research." (2022) 306 *Social Science & Medicine*.

¹⁹⁹ Please see: Angela Sweeney, Peter Beresford. Who gets to study whom: survivor research and peer review processes. . (2020) 35:7 *Disability & Society* 1189-1194; Peter, Beresford. “Developing the theoretical basis for service user/survivor-led research and equal involvement in research” (2005)14:1 *Epidemiologia e Psichiatria Sociale* 4–9”; Sarah Carr ‘I am not your nutter’: a personal reflection on commodification and comradeship in service user and survivor research, (2019) 34:7-8 *Disability & Society* 1140-1153.

²⁰⁰ Papoulias *Supra* note 198.

the research community.²⁰¹ Beresford, also a long standing contributor to the service

user/survivor community, speaks to this point, about the centrality of service user knowledge:

Traditionally, conventional research and researchers appropriated the experience of research participants, arguing that they themselves were better equipped to interpret it because of their own 'distance' from the experience. It is perhaps now time for mental health and other service users to question such assumptions that: the greater the distance there is between direct experience and its interpretation, the more reliable it is, and explore instead the evidence and the theoretical framework for testing out whether: the shorter the distance there is between direct experience and its interpretation (as for example can be offered by user involvement in research and particularly user-controlled research), then, the less distorted, inaccurate and damaging resulting knowledge is likely to be.²⁰²

However, delving into whether there exists a correlation between the closeness of direct experience to its interpretation proves challenging, as the politics surrounding the notion of "evidence" remain deeply politicized. As Mykhalovskiy and Weir note, evidence-based decision making is not a static construct but rather a mechanism that undergoes adaptation as it interacts with various professional cultures and work contexts and these sites of professional work do not monopolize evidence.²⁰³

In Canada, the Tri-Agency Research Integrity Policy sets the standards for research integrity required for funding from the Tri-Council agencies which include the Canadian Institute of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC).²⁰⁴

Popular funding bodies in mental health such as SSHRC and CIHR are governed by statutory

²⁰¹ Diana Rose, "Collaborative research between users and professionals: peaks and pitfalls" (2003) 27, *The Psychiatric Bulletin* at 405.

²⁰² Peter Beresford, "Developing the theoretical basis for service user/survivor-led research and equal involvement in research" (2005) 14: 1 *Epidemiologia e Psichiatria Sociale*, at 7.

²⁰³ Eric Mykhalovskiy and Lorna, Weir L. The problem of evidence-based medicine: directions for social science. *Sep 59:5* (2004) *Soc Sci Med.* at 1067.

²⁰⁴ Government of Canada-the Panel on Responsible Conduct of Research "Tri-Agency Framework: Responsible Conduct of Research (2021)" Government of Canada. online: <https://perma.cc/JLS3-N5LT>

regulations²⁰⁵. In particular, CIHR, a key health research organization, primarily funds evidence-based medical treatments. Yet organizations like CIHR grapple with what is referred to as the "two death valleys" in research dissemination.²⁰⁶ The first valley concerns translating basic research discoveries into practical treatments, while the second relates to sharing research findings with healthcare decision-makers. To fix these issues, CIHR is attempting to focus more on research that involves patients directly through program such as their Strategy for Patient-Oriented Research (SPOR).²⁰⁷ This kind of research looks at how treatments work in real life and helps make sure research results actually get used in health care. To that end, CIHR and SPOR are assessing their progress to consider necessary changes and are leading efforts to refresh a strategy by engaging patients, Indigenous communities, researchers, policymakers, and healthcare professionals nationwide to shape SPOR's future direction with the aim of disseminating a "what we heard" report with the community in early fall 2024.²⁰⁸ Patient engagement regimes, tied to these legal and governmental engagement mandates, overlook informing individuals of their inter-institutional influence and logics. Focusing on including the individual patients looks progressive but can neglect how a group is affected by systemic inequities, perpetuating tokenism and co-optation.²⁰⁹ Psychiatric research or engagement practices appear to facilitate inclusion; however, they concurrently assuage institutional

²⁰⁵ Please see: *Social Sciences and Humanities Research Council Act, RSC 1985, c S-12* and Canadian Institutes of Health Research Act, SC 2000, c 6, LC 2000, ch 6.

²⁰⁶ Canadian Institutes of Health Research (CIHR), (2014) Canada's Strategy for Patient-Oriented Research online: CIHR <https://perma.cc/3CSL-4POF>.

²⁰⁷ Canadian Institutes of Health Research (CIHR), (2024) "SPOR in action" Government of Ontario [<https://perma.cc/VJ8Y-GB5X>].

²⁰⁸ Canadian Institutes of Health Research (CIHR). (n.d.). Refreshing Canada's Strategy for Patient-Oriented Research. online: <https://cihr-irsc.gc.ca/e/53699.html> [<https://perma.cc/DX86-JLUS>].

²⁰⁹ Pauly B, Urbanoski K, Hartney E, Shahram S, Marcellus L, Wallace B, Macdonald M, Hancock T. "What Is Missing from "Patient-Oriented Research?" A View from Public Health Systems and Services". (2019) 15:2 Health Policy.

culpability through the propagation of a particular kind of "engagement washing"²¹⁰ This phenomenon serves to placate unaddressed historical injustices that that have been raised over the years.²¹¹

²¹⁰ Others have noted instances of "pinkwashing" or "greenwashing" by powerful institutions, where civil liberties are superficially acknowledged and promoted to divert attention from actions hostile to such liberties. Pinkwashing exploits support for LGBTQ+ rights, while greenwashing involves misleading claims about environmental benefits. Similarly, "access washing" leverages claims of "accessibility" to justify harm to marginalized communities. Please see: "Notes on "Access Washing" Disability Justice Network of Ontario online: <https://www.djno.ca/post/notes-on-access-washing>. [<https://perma.cc/UA36-EK66>]

²¹¹ Helen Spandler and Mick Mckeown. "Exploring the case for truth and reconciliation in mental health services" (May 2017) 22:2 Mental Health Review Journal.

CHAPTER 2 MEDICO LEGAL BORDERLANDS

We are also committed to accountability and transparency. We have learned that measuring results – and publicly posting those results – drives positive change.

— Deb Matthews Minister of Health and Long-Term Care

In order to understand how patient rights, patient engagement and rationality are currently curated within the nine hospitals discussed in this thesis, I review the evolution of patient bill of rights literature concerning psychiatric patients in Ontario. Following this contextualization, I delve into the tenets of the *ECFAA*. I conclude with a re-counting of the government’s attempt in 2011 to divest the (then) arm’s length Psychiatric Patient Advocacy Office to a mental health agency with a view to demonstrating how the access to advocacy has shifted since the adoption of the *ECFAA*.

2.1 Patient Bill of Rights and Care Covenants

Patient Bills of Rights²¹² have substantially enriched discourse on service user legal history by encouraging exploration into their symbolic and juridical significance. As Flood notes, despite the absence of formal legal entitlements within these types of bill of rights documents, they function as instrumental mechanisms for the cost-effective resolution of individual patient grievances.²¹³ The relevance of this literature to my study lies in exploring the intersection of human rights protections and psychiatric narratives within the institutional frameworks of hospital care, often influenced by government directives.²¹⁴

²¹² Hospitals examined in this studies use various title to describe the name of their name of patients’ rights or care charters. See Appendix A.

²¹³ Colleen M. Flood and Kathryn May. “A Patient Charter of Rights: How to Avoid a Toothless Tiger and Achieve System Improvement.”, (2012)184: 14 Canadian Medical Association Journal.

²¹⁴ For an understanding of the scope of oversight in government governance, please refer to: *The People's Health Care Act, 2019, SO 2019, c 5*.

By examining how bills of rights “perform” we can question the idea that equality is a fixed and unchanging concept. Instead, equality might be viewed as a dynamic and evolving right that varies based on legal and jurisdictional contexts. This view also recognizes that discrimination is not a static problem but one that fluctuates and is influenced by social contexts and hierarchical power structures.²¹⁵ The formalization of patient bills of rights has been demonstrated through various governmental initiatives and the grey literature over the years. In the course of engagement with this literature, I considered whether these documents held genuine potential, while concurrently revealing the unfinished nature of the equity and human rights promises concerning patients of psychiatric services.

2.2 Un-charted: Patient Bills of Rights

An initial endeavour preceding the adoption of the *Canadian Charter of Rights and Freedoms*²¹⁶ occurred in 1979, during which a legislative debate proposed that the government formulate and implement a Patient Bill of Rights. This bill aimed to codify the rights of all patients receiving services from hospitals affiliated with the Ontario Hospital Association. It was asserted during this debate that such a bill was necessary for ensuring patient rights:

That, in the opinion of this House, the government of Ontario should consider the introduction of legislation requiring each governing body of a health discipline to which the Health Disciplines Act, 1974, applies and the Ontario Hospital Association to develop and adopt a patients’ bill of rights codifying the rights of every patient who receives

²¹⁵ Please see commentary on how the concept of equality has always been abstract, since its first decision on section 15 of the *Canadian Charter of Rights and Freedoms* and that the continued demand for a precise definition is often driven by political considerations. Joshua Sealy-Harrington “The Alchemy of Equality Rights.” (2021) 30:2 *Constitutional Forum / Forum Constitutionnel*.

²¹⁶ *Canadian Charter of Rights and Freedoms*, Part I of the Constitution Act 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11 [Charter].

services from a practitioner of that health discipline or from a hospital that is a member of the association.²¹⁷

Other attempts via private members bills to conceptually introduce a bill of rights continued in the years ahead in similarly aligned efforts of vulnerable groups. For instance, in 1994, the government adopted the *Long Term Care Act*²¹⁸ for those receiving health care service in the community. This *Act*²¹⁹ included a section designated as the "Bill of Rights," which articulated "rights" analogous to the language found in contemporary PDoVS for instance, the entitlement to be informed about laws or policies impacting care provided by the service provider, as well as the right to voice concerns regarding service. By 1995, the *Ontario Advocacy Act*²²⁰ had been adopted into law, signifying a stronger commitment and push to promote advocacy and protecting the rights of people with disabilities in Ontario. The goal was to establish a system of general social-advocacy services for vulnerable adults in the province, mirroring the support provided by the Ontario legal aid plan, but focusing on non-legal areas.²²¹ However, it was repealed by the Mike Harris Progressive Conservative government upon their election in 1995. Efforts for rights oversight continued in 1996 with Bill 41²²² (*An Act to Protect the Rights of Persons Receiving Health Services in Ontario*), introduced by Elinor Caplan.²²³ Notably, the College of Physicians and Surgeons of Ontario (CPSO) expressed opposition to this bill, articulating that:

²¹⁷ Legislative Assembly of Ontario, *Patient Bills of Rights Official Records for 7 June 1979*, 31st Parliament, 3rd June 197.

²¹⁸ *Long-Term Care Act*, 1994, S.O. 1994, c. 26.

²¹⁹ *Ibid.*

²²⁰ *Advocacy Act*, 1992, S.O. 1992, c. 26.

²²¹ Ernie Lightman and Uri Aviram. "Too Much, Too Late: The Advocacy Act in Ontario." (2000) 22:1 Law & Policy at 26.

²²² Bill 41, *Patients' Bill of Rights*, Session 1, 36th Parliament, Ontario, 1996 (April 25, 1996 Ordered referred to Committee of the Whole House).

²²³ Elinor Caplan served as Liberal Member of Provincial Parliament from 1985-1997.

The CPSO believes Bill 41 is unnecessarily interventionist, that it will hamper appropriate patient-practitioner relationships, that it unilaterally changes the definition of 'professional conduct,' that it creates a new, mandatory process for complaints, and that it is clearly unreasonable.²²⁴

Bill 41 did not get beyond second reading. In 1998, Marion Boyd²²⁵ introduced Bill 50²²⁶. It was debated on October 15, 1998, and endorsed by members on all sides. However, despite support, the government blocked it from being sent to the standing committee for further consideration.²²⁷ Boyd reintroduced the bill this time, entitled Bill 18, *the Health Care Accountability and Patients' Bill of Rights Act*²²⁸ and it too was defeated with the 1999 election. By 2003, another attempt was made this time by Shelley Martel²²⁹, who moved for the reading of Bill 22 the *Tommy Douglas Act (Patient Bill of Rights)*²³⁰. According to Martel, the bill was exactly the same as the one previously introduced by Boyd, except for two changes: the renaming of the bill to honour Tommy Douglas²³¹ the founder of universal healthcare and the second change a requirement to expand the health care standards to include more health care organizations and providers when developing standards of care.²³²

²²⁴ The Medical Post. "Proposed Opposition Bill Targets Patients' Rights: OMA and Ontario College Dispute Timely Access Clause." (Aug 20, 1996) 32: 28 The Medical Post at 38.

²²⁵ Marion Boyd served as NDP Member of Provincial Parliament from 1990 -1999.

²²⁶ Bill 50, *An Act to promote patients' rights and to increase accountability in Ontario's health care system*, 2nd Session, 36th Parliament, Ontario, October 15 1998 (Second Reading of Bill 50).

²²⁷ Legislative Assembly of Ontario Third Session, 37th Parliament Official Report Journal of Debates (Hansard) Thursday 30 May 2002 (Shelley Martel) at 491.

²²⁸ Bill 18, *Health Care Accountability and Patients' Bill of Rights Act*, 1999 Session 3, 36th Parliament, Ontario April 28, 1999 (First Reading).

²²⁹ Shelley Martel served as NDP Member of Provincial Parliament from 1999–2007.

²³⁰ Bill 22, *Tommy Douglas Act (Patients' Bill of Rights)* Legislative Assembly of Ontario, Third Session, 37th Parliament Thursday 30 May 2002.

²³¹ Ironically, in 1933 Tommy Douglas briefly endorsed eugenic solutions like segregation and sterilization to address what he described in his master's thesis as the "subnormal family" (i.e., families considered mentally or morally inadequate). This view was later regretted by Douglas. Please see: Rev. TC Douglas "The problems of the subnormal family" (Masters Thesis, McMaster University, 1933).

²³² *Supra* at note 227 .

In 2002, the enthusiasm for health care reform across Canada intensified significantly. At the federal level, the Standing Senate Committee on Social Affairs, Science and Technology, chaired by Senator Kirby, released its final report on the state of the health care system in October.²³³ This was soon followed by the final report of Roy Romanow's Commission on the Future of Health Care in Canada in November wherein during the hearings, the Commission heard suggestions for the need of a “Health Covenant” or “Patient Bill of Rights” to set out clear legal rights and obligations, similar to those set out in the *Canadian Charter of Rights and Freedoms*.²³⁴ The journey toward establishing patient bills of rights in Ontario has seen commendable efforts and significant challenges. On the positive side, various legislative initiatives have demonstrated a strong commitment to safeguarding patient rights and ensuring accountability in healthcare, addressing a broad spectrum of patient rights from community care to hospital services. However, there have been notable setbacks. The repeal of the *Advocacy Act*²³⁵ in 1995 by the newly elected Harris government highlighted the vulnerability of such legislative efforts to political changes, undermining robust efforts at rights and advocacy. The piecemeal nature of these efforts over the years suggests a lack of cohesive and sustained progress in establishing a robust Patient Bill of Rights, particularly in the absence of resources and education to support community capacity understanding and implementation. The Roy Romanow Commission of 2002 advocated for the establishment of a national health policy,

²³³ Canada, Standing Senate Committee on Social Affairs, Science and Technology, *The Health of Canadians-The Federal Role: Recommendations for Reform*, vol. 6 (Ottawa: Government of Canada, 2002) (Chair: Hon. Michael J.L. Kirby) [Kirby report].

²³⁴ Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada* (Ottawa: Government of Canada, 2002) (Commissioner: Roy J. Romanow) [Romanow report] at 49.

²³⁵ *Advocacy Act Supra* note 220.

recommending the creation of the Health Council of Canada.²³⁶ Despite its inception, the Council failed to deliver a comprehensive national strategy and has since been dissolved.

Within the context of these governmental initiatives, the promotion of a bill of patient rights by provincial and federal authorities is interwoven with emerging frameworks of patient-centred care. Fundamentally, this approach has emerged and is connected to the notion of involving the public in policy-making processes, emphasizing choice within publicly funded healthcare institutions. These efforts collectively seek to enhance the legitimacy and accountability of public healthcare systems, fostering a more responsive and equitable framework of care.²³⁷ The interplay between “legitimacy” and “patient engagement” presents an interesting (and perhaps insidious) compelling quality. The rise of patient engagement has contributed to a specific form of legitimation because publicly funded healthcare systems are born of the peoples will and crafted for peoples welfare. The theoretical ideal of patient inclusion in decision-making lies in its power to confer legitimacy upon these institutions, affirming their status as true custodians of public trust. But the reality is that as Flood notes, “public involvement is valued in theory, but too frequently sacrificed upon an altar of pragmatism: getting the public involved is considered too complex, too time consuming, too costly and its benefits too nebulous.”²³⁸

As elaborated in the succeeding section, PDoVs, encompassing hospital patient bills of rights, patient charters, or covenants of care, are theoretically designed to be co-produced by patients and the hospital. These documents ostensibly function to foster engagement and confer

²³⁶ Commission on the Future of Health Care in Canada, *Supra* note 234: at 52.

²³⁷ Colleen M Flood, "Scoping the shape of an iceberg: the future of public involvement in health policy: reflecting on 'Public involvement policies in health: exploring their conceptual basis'." (2015) 10:4 Health Economics, Policy and Law at 383

²³⁸ *Ibid* Flood at 382.

legal legitimacy upon a lay populace. However, drawing on Ahmed’s writing on engagement and complaints, which elucidates that policies, procedures, and commitments can be “nonperformative” referring to institutional speech acts that fail to actualize the outcomes they purport to establish.²³⁹ Extending from this premise, I posit that being a good patient/citizen necessitates inhabiting this non-performative sphere— employing the same empty terminologies and phrases, and conforming to institutional discourses in the absence of effective modes of resistance. This critique highlights the inherent instability and performative contradictions within institutional practices and the discursive construction of civic identity.

2.3 The “Excellent Care for All Act” (ECFAA)

The *Excellent Care for All Act* (ECFAA), its scope and implementation in the hospital sector (both general and psychiatric) represents a significant shift in the governance of hospitals and more importantly how “patient consultation” became positioned. The *ECFAA* remains important for matters relating to “inclusion” and “patient engagement” of mental health service users insofar as it represents a legislative definition and directive (paradoxically) in an increasingly austere climate of health service delivery²⁴⁰ all the while stating that it is important to put patients first. Given the adoption of the *Act*, the literature critically analysing its trajectory

²³⁹ Sara Ahmed, *Complaint* (Durham: Duke University Press, 2021) at 30.

²⁴⁰ Janna Klostermann “Fighting privatization & austerity in Ontario healthcare”. Ontario Health Coalition (March 1, 2022) online: Ontario Health Coalition <<https://www.ontariohealthcoalition.ca/index.php/fighting-privatization-austerity-in-ontario-healthcare>> [https://perma.cc/B43V-KSRR]

is still theoretically thin²⁴¹ yet, it remains a relevant piece of legislation given its emphasis on fiscal accountability and requests for transparency in hospital practices.

The *ECFAA* was adopted on June 8, 2010. Its defined purpose was to improve hospital accountability, quality, safety and the overall experiences of patients who access healthcare services²⁴². When the *ECFAA* was initially passed, the *Public Sector Compensation and Restraint to Protect Public Services Act*²⁴³ had already been adopted on May 18, 2010²⁴⁴. This *Act* called for measures for wage restraint in the public sector via the management of compensation for employees and as a result, these two *Acts* announced by government signalled that employee “performance” in the workplace was of utmost importance to the Ministry of Health:

The 2011/12 year marked the first time that performance based compensation was required as part of the *Excellent Care for All Act* (2010). In this second year of *ECFAA*, organizations will be expected to strive towards performance improvement in every aspect of implementation, including performance based compensation²⁴⁵.

The *ECFAA* became linked to the *Public Sector Compensation and Restraint to Protect Public Services Act* because it applied “performance accountability” and subsequent compensation benchmarks as a tenet of excellent health care. Thus, the passing of the *ECFAA* established a

²⁴¹ In reviewing the legal literature on *ECFAA*, I found only a few essays that mention the Act. However, these do not offer a theoretical analysis; instead, they touch on its significance in passing or focus on its fiscal aspects and overall value. Additionally, there are a limited number of legal cases that reference *ECFAA* in footnotes, along with a handful of essays and brief reports from its early years of implementation.

²⁴² *Excellent Care for All Act*, *Supra* note 1 at preamble.

²⁴³ *Public Sector Compensation Restraint to Protect Public Services Act*, SO 2010 c 1.

²⁴⁴ *Bill 16* (An Act to implement 2010 Budget measures and to enact or amend various Acts) included Schedule 24 *Public Sector Compensation and Restraint to Protect Public Services Act*. Please see: Ontario, *Bill 16 An Act to implement 2010 Budget measures and to enact or amend various Acts* 39th Parl, 2nd Sess, (May 18th 2010) at 60. (Hon. D. Duncan) .

²⁴⁵ Ontario Ministry of Health and Long Term Care, *Excellent Care for All Act Updates*, online: <https://web.archive.org/web/20140320210331/https://www.health.gov.on.ca/en/pro/programs/ecfa/legislation/performancecomp/update.aspx> [https://perma.cc/U3XS-84W5].

standard within the hospital sector for all practices and particularly advanced “evidence based” medicine and care. In order to promote these standards it established a number of requirements for hospital compliance. These are set out below as the following:

- establish quality committees that report on quality-related issues;²⁴⁶
- put patient / care provider satisfaction surveys in place;²⁴⁷
- establish a patient relations process to address and improve the patient experience;²⁴⁸
- develop a declaration of values following public consultation, if such a document is not currently in place;²⁴⁹
- put annual quality improvement plans in place and make these available to the public;²⁵⁰
- link executive compensation to the achievement of targets set out in the quality improvement plan.²⁵¹

While all seven requirements warrant consideration, this discussion will concentrate on four specific areas: the role of "quality committees," "quality improvement plans," the patient relations process, and the "declaration of values following public consultation." This focus aims to elucidate the opportunities and limitations inherent in the government's increasing involvement in healthcare administration.

2.4 Quality Committees

As a sub-committee of hospital boards, quality committees are responsible for reviewing matters that address the overall quality of healthcare service delivery. The composition of this committee is comprised of at least one third voting members of the Board. The rest of the committee must include a member of the medical advisory committee, the hospital's chief nursing executive; one person who works in the hospital and who is not a physician or a nurse (this individual can be

²⁴⁶ *Excellent Care for All Act, Supra* note 1.ss.3-4

²⁴⁷ *Excellent Care for All Act, Supra* note 1. s. 5

²⁴⁸ *Excellent Care for All Act, Supra* note 1.s. 6

²⁴⁹ *Excellent Care for All Act, Supra* note 1.s. 7

²⁵⁰ *Excellent Care for All Act, Supra* note 1.s. 8

²⁵¹ *Excellent Care for All Act, Supra* note 1.s.9

either a manager or, an individual who provides direct care)²⁵². Given, the rise of interest in inter-professional practice, individuals with varying skill sets or expertise are usually encouraged as members. As there is no limit to the number of members on this committee, the board has the discretion to appoint other members to the quality committee to meet the needs of the hospital or community.

The quality committee monitors and reports to the board on service issues and overall service quality using data like critical incidents and advice from the medical advisory committee. They collaborate with the board to enhance service quality and ensure that hospitals share best practices through ongoing employee training and information dissemination. As one of the responsibilities of the quality committees is to ensure adherence to “best practices”²⁵³ the Ministry of Health and Long Term Care determined that best practices are suitably met when there is attention to three main areas: patient safety, clinical care and governance²⁵⁴ Yet, the concept “Patient safety” is broadly and inconsistently defined in mental health care.²⁵⁵ Further, in mental health care, there is minimal uptake on how patients may articulate a far wider spectrum of safety-related problems than those defined by government or health researchers – particularly on the matter of coercion.²⁵⁶ The Ministry and affiliated organizations, such as Health Quality Ontario, provide toolkits to enhance understanding and education about patient

²⁵² General, O Reg 445/10, <<https://canlii.ca/t/543tb>>

²⁵³ *Ibid* at ss 3 (4).

²⁵⁴ *Ibid* ss 4(3).

²⁵⁵ On patient safety in mental health please see: Tracy Brickell et al. *Patient safety in mental health*. (Edmonton: Canadian Patient Safety Institute 2009) and, Andrea Waddell. “Patient Safety and Mental Health—A Growing Quality Gap in Canada”(2021) 67:4 *The Canadian Journal of Psychiatry* 247.

²⁵⁶ Please see: Jasna Russo and Jan Wallcraft. “Resisting Variables – Service User/Survivor Perspectives on Researching Coercion.”in Thomas Kallert, Juan Mezzich, and John Monahan *Coercive Treatment in Psychiatry: Clinical, legal and ethical aspects*. Chichester (UK: John Wiley & Sons, Ltd, 2011) at 213 -234, and Lyn Brierley-Jones, Lauren Ramsey, Krysia Canvin, Sarah Kendal, John Baker. “To What Extent Are Patients Involved in Researching Safety in Acute Mental Healthcare?” *Research involvement and engagement* (2022) 8:1

safety. These resources include information from the Canadian Patient Safety Institute (CPSI)²⁵⁷, funded by Health Canada following a 2002 report.²⁵⁸ CPSI and Accreditation Canada aim to help healthcare organizations improve quality, safety, and efficiency.²⁵⁹ Reflecting the trend to incorporate patient perspectives, in 2017, Accreditation Canada began including "patient surveyors" in accreditation inspections. While commendable, there is yet no analysis about how these patient surveyors understand and address human rights concerns and how they might make a connection with the required organizational practice standards (for example in the operationalization of restraints)²⁶⁰. For example, CAMH has received multiple accreditations, yet Accreditation Canada did not identify the disproportionate use of restraints among Black inpatients compared to non-Black patients. The Empowerment Council²⁶¹ persistently advocated for years to obtain demographic data on restraint use, demonstrating its longstanding commitment as an independent advocacy organization.²⁶² However with newly recruited patient initiatives it is unclear what role and feedback, patients or patient advocacy groups play on hospital committees. Service users have discussed difficulties with feeling comfortable in such

²⁵⁷ Now the Canadian Patient Safety Institute is called Healthcare Excellence Canada

²⁵⁸ Canadian Patient Safety Institute, *About CPSI* online: <https://www.healthcareexcellence.ca/en/about/about-us/our-story/> [https://perma.cc/986Z-UWTL]

²⁵⁹ Accreditation Canada, *About Us* online: Accreditation Canada < <https://accreditation.ca/about> > [https://perma.cc/4DJW-43BQ]

²⁶⁰ H. Archibald Kaiser. "Restraint and Seclusion in Canadian Mental Health Facilities: Assessing the Prospects for Improved Access to Justice" *The Windsor yearbook of access to justice* (2001) 19 at 391–417.

²⁶¹ The Empowerment Council has a history at CAMH since 1992 and yet continues to remain underfunded while other institutional and non-independent patient initiatives receive funding.

²⁶² The Office of Health Equity and the Anti-Black Racism and Mental Health Advisory Committee "Dismantling Anti Black Racism" (n.d) online: CAMH <https://www.camh.ca/-/media/files/camh-dismantling-anti-black-racism-pdf.pdf> [https://perma.cc/H8FU-VYGR] at 8.

meetings, experiencing sanism, difficulty with power relationships, or embodying a “service user” identity in such spaces²⁶³

2.5 Quality Improvement Plans

Quality Improvement Plans or “QIPs” as they are colloquially understood in the field are another key and important feature of *ECFAA* legislation. QIPs are a yearly record of hospital goals for quality improvement.²⁶⁴ In the early days of *ECFAA* instruction to hospitals, a working and task group was formed under the direction of the Minister of Health to offer guidance on how to implement and complete the QIPs. QIPs also had to be shaped to allow for comparison across the province with a core set of indicators that are relevant to all hospitals.²⁶⁵

The Ontario Liberal government built changes for better hospital accountability on a foundation of measurement and evidence, integration, and practise improvement, all of which were implemented through the province. Emphasis was devoted to the "pay for performance" that QIPs gave in the early years, with the linkage to advancement being related to CEO salary, and this was supported in early 2011 and 2012 by increased media coverage on high hospital CEO salaries.²⁶⁶ Currently, mechanisms for assigning responsibility and enforcing sanctions for poor performance have shown ineffectiveness. Structural governance changes, such as the Progressive Conservative Party's election and dismantling of the previous LHIN governance model, have compounded difficulties in assessing the true adherence to patient safety, quality improvement, and patient rights. Several studies have indicated that increasing quality

²⁶³ Liz Brosnan, “The Lion’s Den’: The Epistemic Dimensions of Invisible Emotional Labour in Service-User Involvement Spaces” in Jijian Voronka and Lucy Costa, "Disordering social inclusion: Ethics, critiques, collaborations, futurities." (2019) 6 Special issue of *Journal of Ethics in Mental Health*.

²⁶⁴ *Excellent Care for All Act*, *Supra* note 1 at ss8.1

²⁶⁵ Sudha Kutty, Nizar Ladak, Cyrelle Muskat, Jillian Paul and Margo Orchard. “The Excellent Care for All Act’s Quality Improvement Plans: Reflections on the First Year” (2012) 15:Spec. Ed.3 *Healthcare Quarterly* 33–37. At 34.

²⁶⁶ Karen Howlett, Carys Mills. “New rules mean salary cuts for hospital executives.” *The Globe and Mail* (5 January 2012) at A8 .

improvement capacity may improve some quality outcomes however, there has not been a clear focus on determining how much the system benefits from all these investments (for example, staff training, e- learning, program development etc.) resources, and expenditures.²⁶⁷ And more to the point, it is possible that CEOs are simply too detached from the patients they serve to have an impact on patient satisfaction.²⁶⁸ However, in 2014, the MOHLTC aimed to strengthen the role of patients by amending the patient relations process by ensuring that quality improvement plans included patient feedback.²⁶⁹

2.6 Patient Relations

Prior to the *ECFAA*²⁷⁰ many hospitals had a process by which they obtained complaints or compliments from their patients but the passing of the *ECFAA* required that each hospital consult with patients and community stakeholders when creating a patient declaration of values (or patient bill of rights, or philosophy of care document). The PDoVs are made available to the public and used to direct the hospital's patient relations processes and feedback to annual quality improvement work.²⁷¹

²⁶⁷ Please see: Brian M Wong, et al. "Building the bridge to quality: an urgent call to integrate quality improvement and patient safety education with clinical care." (2020) 95:1 *Academic Medicine*; and Yee-Ching Lilian Chan, and Sylvia Hsingwen Hsu. "Target-Setting, Pay for Performance, and Quality Improvement: A Case Study of Ontario Hospitals' Quality-Improvement Plans." (2019) 36: 1 *Canadian Journal of Administrative Sciences/Revue Canadienne des Sciences de l'Administration*; and, Mery, Gustavo et al. "Evaluating investment in Quality Improvement Capacity Building: A systematic review" (2017) 7:2 *BMJ Open*.

²⁶⁸ Akingbola, Kunle & Herman A van den Berg. "Does CEO compensation impact patient satisfaction?" (2015) 29:1 *Journal of Health Organization and Management* at 111.

²⁶⁹ Government of Ontario, *New proposed regulation under the Excellent Care for All Act, 2010: Strengthening the Patient Relations Process in Ontario's health care organizations online*: <http://www.ontariocanada.com/registry/view.do?postingId=15702&language=en> [<https://perma.cc/XGM2-CC9Z>].

²⁷⁰ *Excellent Care for All Act*, *Supra* note 1.

²⁷¹ Ontario Ministry of Health and Long Term Care, *Guidance Document for the Declaration of Values ECFAA Requirement*, (Ontario: November 2010) at 2 ss 2.2 online:

While PDoVs are made available to the public on hospital websites etc., what is less transparent is the accessibility of data on complaints themselves. It is also important to note, that patient relations offices are an extension of the hospital themselves and as such, do not operate independently of hospital interests. The patient relations process in psychiatric facilities is more akin to a “customer service” office. Effective interventions to enhance patient complaint experiences require comprehensive, integrated, context-specific, and accessibility of the information on how to complain²⁷². Finally, while outside the purview of this thesis, my twenty-plus-year tenure in hospital settings and involvement in staff hiring interviews for patient relations reveal a clear prioritization of candidates with medical clinical experience for these roles, to the exclusion of other disciplines. This implies that “clinical” skills are considered essential for addressing complaints within the hospital.

2.7 Patient Declaration of Values

As mentioned, another stipulation of the *ECFAA*²⁷³ is that hospitals demonstrate they opted into a Patient Declaration of Values ((PDoV) shaped by public consultations²⁷⁴ and that it be available and accessible to the public²⁷⁵. *ECFAA* legislation required that all hospital have their PDoV available to the public by June 8, 2011. An added responsibility is that hospitals must ensure their respective patient relations (complaints office) process reflect the content of its

www.health.gov.on.ca/en/pro/programs/ecfa/legislation/patientvalue/guide_patient_dec_e.pdf
[<https://perma.cc/YA25-B6LX>].

²⁷² Tolib Mirzoev and Sumit Kane, “Key Strategies to Improve Systems for Managing Patient Complaints Within Health Facilities - What Can We Learn from the Existing Literature?” (2018) 11:1 *Global Health Action*.

²⁷³ *Excellent Care for All Act*, *Supra* note 1.

²⁷⁴ “Public” defined as patients, caregivers, patient advocacy groups, or the broader public connected to the hospital community.

²⁷⁵ *Excellent Care for All Act*, *Supra* note 1. ss 7.

patient declaration of values²⁷⁶. In my initial review of 70 schedule 1 facilities and more pointedly the subsequent nine for this study, I found that most hospitals did have a declaration of values, or something similar such as a patient bill of rights and responsibilities.²⁷⁷

The *ECFAA*²⁷⁸ demonstrated some degree of flexibility with PDoVs by stipulating that what hospitals actually name²⁷⁹ their declaration of values is not important but instead that the document be made available and accessible to the public (via websites, posters, brochures) and, it must have been created in consultation with the service users of the hospital and the process be documented with reasonable detail²⁸⁰. The consultative process was to accord the legislation opportunity to: “empower and inform” Ontarians,²⁸¹ and meant to be a process whereby citizens felt they were “advising and understanding” regarding what to expect from their health care organizations. The consultation was also intended to improve relationships throughout the hospital community. In the 2010 *Guidance Document* for the declaration of values, ideals such as voice, respect, quality, engagement, participation, and information were offered as guiding principles for reference to hospitals wanting to understand and align patient experiential feedback with the legislation.²⁸² The *Guidance Document* also permitted hospitals to employ different terms like "a bill of rights," "philosophy of care," or "patient code of conduct" to

²⁷⁶ *Excellent Care for All Act*, *Supra* note 1 at ss 6 (2).

²⁷⁷ Review of 70 schedule 1 facilities first conducted in 2014 and again in 2022.

²⁷⁸ *Excellent Care for All Act*, *Supra* note 1.

²⁷⁹ The *Act* describes this under their header “Naming Conventions”

²⁸⁰ Ontario Ministry of Health and Long Term Care, *Guidance Document for the Declaration of Values ECFAA Requirement*, (Ontario: November 2010) At 2 ss 2.2 online:

www.health.gov.on.ca/en/pro/programs/ecfa/legislation/patientvalue/guide_patient_dec_e.pdf
[<https://perma.cc/YA25-B6LX>].

²⁸¹ *Excellent Care for All Act*, *Supra* note 1. ss7.

²⁸² Ontario Ministry of Health and Long Term Care, *Guidance Document for the Declaration of Values* *Supra* note 12. at 5 ss 4.2.

articulate their values.²⁸³ However, the diverse titles carry varied implications; for instance, a "philosophy of care" differs from a bill of rights as "philosophy of care" sets the tone for an institution's beliefs and principles guiding patient care, reflecting its ethos and approach whereas a "bill of rights" can specify patients' entitlements and protections within healthcare settings, often with legal implications. In regards to care and rights, the Psychiatric Patient Advocate office had been instrumental in addressing concerns pertaining to the quality of patient care and safeguarding patient rights. However, with the advent of the *ECFAA* the office's efficacy in conducting advocacy has been significantly diminished, diverging from its original mandate particularly in respect to being an independent voice for patients.

2.8 The Psychiatric Patient Advocate Office

*Neutrality and independence will be vitally important if the patient advocate is to be seen as a true safeguard for patients' rights.*²⁸⁴

At the genesis of the Psychiatric Patient Advocate Office (PPAO) a chorus of voices including the patients' rights movement, volunteer groups, media entities, and unions influenced its formation. A call for advocacy within psychiatric hospitals was imperative, due to growing concern regarding the calibre of mental health services, inadequacies in community-based support systems and the need for divestment from the Ministry of Health from the direct management of the provincial psychiatric institutions.²⁸⁵ Here, I provide a pivotal overview of the PPAO, delineating its contemporary status to better understand the current landscape of patient rights access within hospital settings, despite the values espoused in PDoVs.

²⁸³ In the section on "Compliance" in the guidance document, there is a reference to the Patient Declaration of Values (PDoVs), which includes "content appropriate to a patient declaration of values," although it does not specify what "appropriate" means. *Ibid Guidance Document for the Declaration of Values ECFAA* at ss 2.2.

²⁸⁴ Rosalie S. Abella. *Access To Legal Services By The Disabled - Report Of A Study By Judge Rosalie S. Abella.* (Queen's Printer for Ontario.1983) at 48.

²⁸⁵ *Agenda for Action.* (Toronto: Ontario Council of Health, 1979). Recommendation 17.

The psychiatric patient advocate office was formed by the Ontario government in November 1982 as a provincial program to safeguard the rights and privileges of patients in the provincial psychiatric hospitals. Dr. Ted Turner, a Toronto general practitioner was appointed the program's provincial coordinator and eleven patient advocates were hired by May 1983 and would report directly to the provincial coordinator who in turn reported to the Deputy Minister of Health. The advocates were to provide a "patient friend" who would explain the patient's rights and serve as a liaison between the patient and the clinical staff.²⁸⁶ Under Section 9 of the *Mental Health Act*²⁸⁷ designated advocates have the authority to conduct comprehensive inspections in psychiatric facilities including interviewing patients, reviewing documentation, assessing the facility's condition, and investigating matters related to patient care standards, such as staff adequacy and service scope.

PPAO advocacy services are governed by a memorandum of understanding (MOU) between the Ministry and public hospitals. The PPAO's mandate was at one time quite robust championing the legal and civil rights of patients in psychiatric hospitals through individual and systemic advocacy. The PPAO also facilitated self-advocacy and addressed complaints by negotiating patient instructions, investigated incidents, evaluating institutional responses, and providing referrals to external advocacy resources.²⁸⁸ Furthermore, the PPAO engaged in public education initiatives and, (at one time) bolstered by in-house legal counsel, actively partook in tribunal and court proceedings, advocating for patient rights as necessitated. This was exemplified by actions such as petitioning for leave to intervene in tribunal proceedings, as

²⁸⁶ Simmons, *Supra* note 114 at 233.

²⁸⁷ *Mental Health Act* (R.S.O. 1990, c. M.7) at ss 9(2).

²⁸⁸ Robert Buckingham. *Bringing Balance to Mental Health Care: Consumer/Survivor Empowerment in the Psychiatric Hospital System*. (Toronto, Ont: Psychiatric Patient Advocate Office, 1994).

witnessed in the case of Braithwaite and Illingworth²⁸⁹ alongside its involvement in higher court cases,²⁹⁰ inquests,²⁹¹ feedback to the media at times²⁹² and participation in numerous law reform initiatives.²⁹³ Furthermore, the PPAO had historically issued anniversary reports²⁹⁴ featuring contributions from various stakeholders within the field. However, a publicly accessible equivalent has not been made available since the final publication in 2008. In 2011, a year after the *ECFAA*²⁹⁵ received royal assent, the Ministry of Health released a press statement about the divestment of the Psychiatric Patient Advocate Office.

The significance of the PPAO to this study and its inquiries lies in the contrast between assertions positing the rise of patient engagement as a “revolutionary” concept²⁹⁶ with the diminishment of an autonomous entity dedicated to interfacing with the realms of medicine and law to offer feedback on patient experiences both within and beyond the hospital. The

²⁸⁹ *Braithwaite v. Ontario* (Attorney General), 2005 HRTO 32 (CanLII).

²⁹⁰ Please see: *Pinet v. Mental Health Centre, Penetanguishene*, 2006 CanLII 4952 (ON SC).

²⁹¹ For instance please see: *Cinderella Allalouf Ad-Hoc Litigation Committee v. Lucas*, 1999 CanLII 18723 (ON SCDC) or, Verdict of the Coroners Jury. “Inquest into the death of Jeffrey James” (November 21st 2008).

²⁹² For a discussion on how more than a dozen Canadians told the Psychiatric Patient Advocate Office that they were blocked from entering the United States after their records of mental illness were shared with the U.S. Department of Homeland Security, please see: Sarah Bridge “Canadians with mental illnesses denied U.S. entry” (Sep 09, 2011) CBC News <Online: <https://www.cbc.ca/news/canada/canadians-with-mental-illnesses-denied-u-s-entry-1.1034903> > [<https://perma.cc/8C5K-9X7W>].

²⁹³ The PPAO made submission for example to the to the 1990 Weisstub Report on treatment incapacity, health information privacy legislation, and Bill 68, which expanded the civil commitment criteria and introduced community treatment orders, which require that patients in the community comply with a treatment plan. Please see: David N. Weisstub, *Enquiry on Mental Competency: Final Report* (Toronto: Publications Ontario, 1990).

²⁹⁴ Please see for example: Psychiatric Patient Advocate Office, *Mental health and Patient Rights in Ontario, Yesterday, Today and Tomorrow. 20th Anniversary Special Report* (Queens Printer, May 2003); Psychiatric Patient Advocate Office, *Honouring the Past, Shaping the Future: 25 Years of Progress in Mental Health Advocacy and Rights Protection : Psychiatric Patient Advocate Office 25th Anniversary Report* (Queen’s Printer for Ontario, 2008).

²⁹⁵ *Excellent Care for All Act*, *Supra* note 1.

²⁹⁶ Tessa Richards, Victor M. Montori, Fiona Godlee, Peter Lapsley, and Dave Paul. "Let the patient revolution begin." (2013). *Bmj* at 346.

widespread alarm and loud outcry²⁹⁷ witnessed during efforts to safeguard the PPAO underscored the pressing appeal for an independent regulatory entity within the healthcare sector

2.9 The Coalition for an Independent Psychiatric Patient Advocacy Office

On June 28, 2011, Assistant Deputy Minister in Direct Service Provision Patricia Li²⁹⁸ issued a press release about the divestment transfer of the Psychiatric Patient Advocate Office (PPAO) out of the Ministry of Health to the Canadian Mental Health Association- Ontario (CMHA).²⁹⁹ Immediately after this announcement a resolute effort by several stakeholders took hold to resist and prevent the transfer of the PPAO advocacy operations to the CMHA.³⁰⁰ The combined endeavours of service user and mental health agencies, professors and lawyers and advocacy organizations, among other stakeholders, contributed to a group of complaints which pushed the Ministry to alter its trajectory for divestment.³⁰¹

The CMHA a non-profit, charitable organization established in 1952 has a mandate to develop mental health and addiction policy at the provincial level. CMHA Ontario supports 30 local CMHA branches³⁰² in enhancing their governance structures, leadership, and service delivery practices for mental health and addiction clients. One of the most contested issues

²⁹⁷ Numerous individuals and professional organizations expressed their concern and opposition to the divestment, including the Registered Nurses' Association of Ontario, the Ontario Association of Social Workers, 41 psychiatrists and psychiatry residents. The Toronto Board of Health accepted a motion urging the MOHLTC to establish the PPAO as an independent advocacy office. Additionally, the Center for the Human Rights of Users and Survivors of Psychiatry, the Mental Health Bar, and numerous media outlets covered the story of the potential merger.

²⁹⁸ Patricia Li was Assistant Deputy Minister, Direct Services Division Ministry of Health and Long-Term Care 2010- 2011.

²⁹⁹ Carol Goar, "Ontario Takes a backward step on mental health" *Toronto Star* (13 July 2011) at A15 online: The *Toronto Star* < https://www.thestar.com/opinion/goar-ontario-takes-a-backward-step-on-mental-health/article_5edede38-650d-5012-9021-829042ee2e69.html > [<https://perma.cc/5HFP-EPLH>].

³⁰⁰ *Ibid* Goar.

³⁰¹ Helen Henderson, "Rallying care, support for Ontario's psychiatric patients" *Toronto Star* (August 6, 2011), Sec. Living at L10.

³⁰² CMHA branches provide direct mental health services such as case management, housing support, and community treatment orders.

during the dispute to prevent the divestment of the PPAO to CMHA Ontario revolved around whether such a transfer represented a conflict of interest. Proponents of the divestment argued that since the Ministry of Health had directly overseen provincial psychiatric hospitals for over two decades without compromising the PPAO's integrity, CMHA Ontario could similarly manage the portfolio without conflict, as they did not administer or oversee community mental health services. The Ministry shared this perspective. However, many stakeholders, disagreed, contending that such a transfer did indeed pose a conflict, especially concerning the advocacy on specific mental health treatment issues such as Community Treatment Orders, which CMHA branches were involved in and continue to be involved in via case management. In contrast, in 1999, the PPAO opposed the implementation of Community Treatment Orders (CTOs) and advocated for the establishment of a Mental Patients' Bill of Rights, rather than supporting more coercive legislation.³⁰³

In response, a coalition, the Coalition for Independent Psychiatric Patient Advocacy (CIPPAO) emerged, establishing a website and Facebook page, and launching a campaign aimed at informing the public and persuading the Ministry to reconsider its decision.³⁰⁴ Many individuals and approximately forty organizations such as *Ontario Public Service Employees Union* (OPSEU), York University, Ryerson University (now Toronto Metropolitan University) and Community Legal Clinics (to name just a few) wrote letters to deter the transfer. Correspondence from Ted Ball, former Chief of Staff and Senior Policy Advisor to Minister of Health Larry Grossman, founder of the Psychiatric Patient Advocate Office, was notably

³⁰³ “Ontario patient advocates call for mental patients bill of rights instead of new forced treatment measures” (Aug 16, 1999) 15: 1 Community Action (Don Mills, Toronto) at 8.

³⁰⁴ For a list of activities of the Coalition for an Independent Psychiatric Patient Advocate office please see: “Coalition for an Independent PPAO” archived online at: [<https://perma.cc/3UHE-DJCL>]

poignant. Ball reminded the Minister's office of Grossman's vision: a mental health system where individuals could access advocacy services and receive professional assistance to navigate the system independently of system managers, service providers, and policymakers.³⁰⁵ Letters, news coverage, and social media attention placed the Deputy Minister's office in a challenging position, compounded by a looming October provincial election. Strong statements from health critics such as Christine Elliot³⁰⁶ of the Progressive Conservative provided leverage during negotiations to stop the divestment³⁰⁷ and Peggy Nash³⁰⁸ of the New Democratic Party promised to ensure that independent advocacy for psychiatric survivors remained intact because she believed it saved lives.³⁰⁹ The Liberals were aware that criticism regarding the lack of consultation with mental health service users and stakeholders regarding the divestment of the PPAO would convey the message that "vulnerable patients" were at risk of abuse and rights violations. On July 29, 2011, the Honourable Minister of Health, Deb Mathews, announced that changes to the PPAO would not proceed as planned, recognizing the need for further dialogue and consultation. She expressed gratitude for the interest and dedication shown towards the issue, emphasizing that more extensive discussion was required before moving forward.³¹⁰ She also promised:

³⁰⁵ Divestment of the Psychiatric Patient Advocate Office (correspondence via email from Ted Ball July 12, 2011).

³⁰⁶ Christine Elliot was Member of the Ontario Provincial Parliament and served as the Deputy Leader, Official Opposition and Health critic from July 27, 2009 – September 7, 2011.

³⁰⁷ Johanna Weidner, "Changes to mental health system watchdog could threaten independence: Elliot" *Durham Business Times* (July 21, 2011) Final Edition, page 1.

³⁰⁸ Peggy Nash was the New Democratic Party (NDP) Member of Parliament (MP) for the Parkdale—High Park electoral district in Toronto, and was the Official Opposition's Industry Critic.

³⁰⁹ John Bonnar, "Psychiatric survivors continue to fight against the stigma of mental illness" *Rabble News* (July 19, 2011) Online: <https://rabble.ca/human-rights/psychiatric-survivors-continue-fight-against-stigma-mental-illness> [https://perma.cc/8QHR-WXJF].

³¹⁰ Carol Goar, "Reprieve for mental health guardian" *The Toronto Star*, (August 5, 2011) Sec. Opinion at A19.

We will engage our partners across the sector, including patients and their advocates to determine the best way to achieve our shared goals of increased independence for the PPAO. Through the fall we will consult, and make a decision based on your best advice, moving forward with a finalized plan in the winter.³¹¹

Following the Ontario Liberal Party's election on October 6, 2011, the pledged consultation failed to materialize. On March 3, 2012, letters from the CIPPAO were dispatched to a senior policy advisor to the Minister of Health's office, seeking clarification on the promised consultation and raising additional concerns, regarding various aspects of the PPAO operations and actions. These included questions about the lack of updates and information on the PPAO website and its strategic directions, the abandonment of intervention in a Human Rights Tribunal case³¹², the failure to request standing in an inquest³¹³ withdrawal from the Police Records Check Coalition, the absence of legal counsel on staff, and the timing of the promised Ministry of Health and Long-Term Care's consultation.

On June 4th 2012, the CIPPAO received a response from Patricia Li's office stating that the PPAO was not expected to participate in all mental health investigations, that the inquest was adequately served by the Coroner and other parties. The PPAO's advocacy regarding police Records Checks was deemed concluded. Presently, any legal matters within the PPAO office must be directed to managers, who then forward them to a lawyer employed by the Ministry of Health. The significance of the withering away of the PPAO within the scope of my thesis lies in its challenge to prevailing ideologies surrounding contemporary patient engagement frameworks, which posit “engagement” as integral notions of a type of patient-centred deliberative

³¹¹ Letter from Minister of Health Deb Matthews to Lucy Costa July 29th, 2011.

³¹² Please see: *Marshall v. Durham Regional Police Service*, 2011 HRT0 898 (CanLII).

³¹³ The PPAO had aimed to participate in Mr. Kulmiye Aganeh's inquest. Mr. Aganeh died in March 2009 while in custody at the Oakridge Centre for Mental Healthcare now called Waypoint Centre for Mental Health Care (Penetanguishene). Mr. Aganeh died of heart failure owing to toxicity from an antipsychotic after an incident involving restraints.

democracy—a notion that implies active participation in healthcare decision-making processes. The PPAO now operates under a much more limited mandate and no longer advocate as they once did. The *ECFAA*, through its various mechanisms such as hospital quality committees, now manages patient experience within its scope of work.

Chapter 3

THEORETICAL FRAMEWORKS

*While the absence of first-person knowledge is increasingly being identified, the distinctiveness of this epistemic source is not recognized—and its crucial mismatch with the dominant methods of knowledge-making on madness and distress is not being adequately addressed.*³¹⁴

This section delineates the methodological framework used in the analysis of my research and in substantiating the argument that the *ECFAA*³¹⁵ and the Patient Declarations of Values (PDoVs) create a contemporary lexicon that shapes patient voice and both promotes and obfuscates access to patient rights. This thesis adopts Mad Studies as its theoretical lens. In this chapter I will discuss some conceptual tenets of Mad Studies and how it can be applied to the findings of this study. Secondly, I discuss how standpoint theory in combination with Mad Studies' conceptual frameworks informed my research.

3.1 What is Mad Studies?

Mad Studies, critically investigates the ontological, epistemological, and pedagogical claims of normative curricula and psy-logics.³¹⁶ Like Disability Studies, it argues for a “curriculum about curriculum” exploring knowledge creation inside classrooms as well as the implications for that knowledge beyond the classroom.³¹⁷ There are a number of conceptual tenets that are central³¹⁸

³¹⁴ Jasna Russo “Psychiatrization, Assertions of Epistemic Justice, and the Question of Agency.” (2023) 8 *Frontiers in Sociology* at 3.

³¹⁵ *Excellent Care for All Act*, *Supra* note 1.

³¹⁶ Drawing from Foucault, Nikola Rose argues that the growth of the "psy" sciences has a deep connection to transformations in governmentality, and in the theories and technologies of political power. Please see: Nikola Rose, “Governing the soul – a quarter of a century on” (2016) 4:4 *Self & Society*.

³¹⁷ Nirmala Erevelles, Elizabeth J. Grace and Gillian Parekh. "Disability as meta curriculum: Ontologies, epistemologies, and transformative praxis." (2019) 49:4 *Curriculum Inquiry*.

³¹⁸ Mad Studies is evolving and includes multi-discipline interfacing and as such discussions of what should be central areas of debate. For example, contributions to "mad theory" have emerged from Mad Studies projects analyzing histories of madness and psychiatry. These efforts, led by activists and scholars, including Black Indigenous and People of Colour who, advocate for a more robust historiography of Mad people. Despite the disproportionate impact of psychiatric violence on racialized bodies, structural racism and colonialism further

to the work of Mad Studies but I will focus specifically on four for the purposes of examining PDoVs. These theoretical concepts include: Mad activist praxis, service user epistemology, epistemic injustice and sanism. I adopted this theoretical frame due to its capacity to challenge structural prejudices but also its potential to query whose “lived experience”, whose values and what praxis is marshalled to plead a case for high quality, accessible, equitable, patient care in the PDoVs and mental health care more broadly.

3.2 Mad Activist Praxis – Mobilising Human Rights

By moving away from more narrowly medical, legal, and identity-based conceptions of psychiatric disability, or psychiatric patients as objects of study, the scholarship and activism in Mad Studies broadens the analysis and praxis options available for service users³¹⁹. In addition to being committed to addressing rights violations, mad activist praxis is a conceptual framework (international in scope) which draws on its historicity by fostering community and capacity building and, when necessary, using legal mobilisation to advance human rights³²⁰.

Early years of activist praxis made the case for human rights against a custodial context whereby psychiatric medicine held the conviction that psychiatric patients should be contained, controlled as though they were not human, did not have common needs and where emphasis on

marginalize these experiences and as such necessitates an analysis of the erasure of the experiences of racialised mad people even more so than those of white mad subjects. For further reading please see: Rachel Gorman and Brenda A. LeFrançois. "Mad studies." in Bruce Cohen ed. *Routledge International Handbook of Critical Mental Health*. (London: Routledge, 2018).

³¹⁹ Sarah N. Snyder, Kendra-Ann Pitt, Fady Shanouda, Jijian Voronka, Jenna Reid & Danielle Landry “Unlearning through Mad Studies: Disruptive pedagogical praxis” (2019) 49:4 Curriculum Inquiry.

³²⁰ Bonnie Burstow, “From ‘Bed-Push’ to Book Activism: Anti/Critical Psychiatry Activism” in Ruth Kinna, Uri Gordon eds. *Routledge Handbook of Radical Politics. 1st ed.* (New York: Routledge, 2019) at 82.

security over patient comfort was prioritized.³²¹ To some extent, these sentiments, while antiquated, are still active today despite efforts to standardize values across hospitals.³²²

Reaume suggests that while early writings on madness were predominantly from privileged white authors, there has been a broadening of voices since the late 19th century, reflecting diverse experiences in terms of class, gender, and to some extent, race and disability. These writings, along with the efforts of unrecognized activists throughout history, paved the way for what is now known as "Mad Studies".³²³ In parallel with concurrent social movements, the late 1960s and 1970s witnessed the emergence of activist endeavours within the psychiatric patient community. This period was characterized by the transformation of "Negro civil rights" into "Black liberation," the shift from "the rights of women" to "Women's Lib," and the discourse surrounding "gay liberation" among gay men and lesbians.³²⁴ This activist patient praxis has remained a steadfast feature within the work of Mad Studies including organizations representing service users across the globe.³²⁵ For instance, in Latin America social movements have been organising for discourse alternatives to the conventional mental health discourse; the first protest against electroshock and the first "Mad Pride" march were both held in Santiago, Chile, in 2015

³²¹ Nick Crossley, *Contesting Psychiatry Social Movements in Mental Health*. (Oxfordshire: Routledge 2006) at 50.

³²² Examining several hospital inquests, such as those of Jeffrey James and Nikolaos Mpelosas, reveals instances of medical errors and negligence. Another poignant example is the case of Ashley Smith, who tragically died at the age of 19. While in custody, Ashley received multiple psychiatric diagnoses, and staff were instructed to "withhold warmth" from her. For a detailed analysis, please refer to Tess Sheldon et al., "Uncovering Law's Multiple Violences at the Inquest into the Death of Ashley Smith," in Andrea Daley, Lucy Costa, and Peter Beresford eds. *Madness, Violence, and Power: A Critical Collection* (Toronto: University of Toronto Press, 2019), at 198.

³²³ Geoffrey Reaume "The Qualitative Historical Origins of Mad Studies in Word and Deed, 1436–1914." (2024) Qualitative Inquiry.

³²⁴ Duncan Scott Campbell's PhD dissertation: "Unsettled: Discourse, Practice, Context, and Collective Identity Among Mad People in the United States, 1970–1999." (PhD, York University, 2011) Unpublished. is a tremendous and thorough text documenting early activist history via the evolution of Madness Network news, founded in 1972 was an anti-psychiatry journal that served as the focal point for organizing throughout North America, and overseas.

³²⁵ Please see: Transforming Communities for Inclusion (TCI) is a post-CRPD movement of persons with psychosocial disabilities and its cross-disability supporters. It is a membership-based global OPD (Organization of persons with disabilities).

fighting for rights and demonstrating resistance in public spaces.³²⁶ Although Mad Studies has faced criticism regarding its representation and essentialist tendencies,³²⁷ it has consistently shown dedication to amplifying the voices of individuals with lived experience, disseminating knowledge to combat discrimination, and advocating for the rights and objectives of service users. Thus, this is a praxis and discipline dedicated to social justice and activism, in collaboration with other similarly aligned communities of practice, disciplines, and academia at large.³²⁸

Typically this advocacy praxis³²⁹ has included such activities as writing letters, petitioning, influencing public policy and contacting legislators at various levels of government.³³⁰ While various forms of activist praxis can be invoked to address problems and human rights violations, the reliance on law cannot be understated given that, “wicked men will enact wicked rules which others will enforce”³³¹ or, to draw from one psychiatric patient’s words more succinctly, “I backed into the corner of my room. I told them that I disagreed with the legislation that empowered them.”³³² “Excellent care” as described in the *ECFAA*³³³ and “patient

³²⁶ Juan Carlos Cea Madrid "Latin-American Mad Studies: Conceptual Frameworks and Research Agenda" (2022) 32:4 *Physis - Revista de Saúde Coletiva*.

³²⁷ Rachel Gorman and Brenda A. LeFrançois. "Mad studies." In Bruce Cohen ed. *Routledge International Handbook of Critical Mental Health*. (London: Routledge, 2018).

³²⁸ Jasna Russo and Peter Beresford. *The Routledge International Handbook of Mad Studies*. (Taylor and Francis, 2021).

³²⁹ Peter Beresford. *A Straight Talking Introduction to Being a User of Psychiatric Services* (Monmouth: PCCS Books, 2010).

³³⁰ Advocacy praxis occurs within service user organisations (particularly non-profit) representing service users or more to the point, service users themselves can initiate this work. One of my more powerful experiences of patient advocacy was witnessing a number of inpatients organising their own internal petition to protest CAMH hospital cuts to recreation/sports programs. For further reading on activist and advocacy challenges please refer to Nick Mulé and Gloria DeSantis. *The Shifting Terrain : Non-Profit Policy Advocacy in Canada*. (Montreal: McGill-Queen’s University Press, 2017).

³³¹ Herbert L. A Hart, *The Concept of Law* 3rd ed. (Oxford: Oxford University Press, 2012).

³³² Mick Mckeown, et al. “Coercive Practices in Mental Health Services: Stories of Recalcitrance, Resistance, and Legitimation.” in Andrea Daley, Lucy Costa, and Peter Beresford eds. *Madness, Violence, and Power*. (Toronto: University of Toronto Press, 2019) at 345.

³³³ *Excellent Care for All Act*, *Supra* note 1.

values” inhabit a liminal space, parsed from frontline work and clinical practices³³⁴ the management of inpatient units or the tribunals patients attend. This is an important implication for understanding assumptions in well intentioned legislative aims (like the *ECFAA*). This research demonstrates how patients can be so central in documents and yet also erased, particularly those forms of patient voice that deviate from the lexicon in PDoVs.

While disability law has to some extent flourished over the last twenty years,³³⁵ legal mobilisation and the link to mental health service users, as well as Mad Studies as a discipline or as an ongoing activist praxis, have not fared as well in comparison to disability law.³³⁶ Vanhala makes this point when she discusses that those who are active in mental health human rights work criticise how law on issues of disability frequently fail to take into account the variety of experiences of mental distress and more pointedly how mental health rights may exist in theory but do not actually always exist in practice.³³⁷ In earlier years of service user activism and praxis in Ontario, alliances were forged between service user/survivor activism and lawyers to facilitate legal mobilization. For instance, in the landmark case of "Mrs. T," a hospitalized patient contested a review board treatment order for Electroconvulsive Therapy (ECT).³³⁸ In 1983, concurrent with the case proceedings, a consortium of electroshock survivors, advocates, and

³³⁴ Glenn E. Randall, Patricia Wakefield, Neil Barr, et al. “Barriers to Implementing Patient-Centred Care: An Exploration of Guidance Provided by Ontario’s Health Regulatory Colleges” (2020) 28 *Health Care Anal.*

³³⁵ Please see for instance: Katherina Heyer, *Rights enabled: the disability revolution, from the US, to Germany and Japan, to the United Nations*. (Ann Arbor: University of Michigan Press, 2015) and Doron Dorfman “Re-claiming disability: identity, procedural justice, and the disability determination process” (2017) 42:1 *Law & Social Inquiry* as well as Vanhala *Supra* note 196 as multidisciplinary works that combine socio legal literature on rights and legal mobilisation with an analysis of disability and Disability Studies.

³³⁶ Lisa Vanhala & Jacqueline Kinghan “The ‘madness’ of accessing justice: legal mobilisation, welfare benefits and empowerment” (2022) 44:1 *Journal of Social Welfare and Family Law*.

³³⁷ *Ibid.*

³³⁸ *Re T and Board of Review for the Western Region et al.*, 1983 CanLII 1924 (ON SC), <<https://canlii.ca/t/g14qb>> retrieved on 2023-03-11.

scholars established the Ontario Coalition to Stop Electroshock.³³⁹ This coalition's inception followed a public symposium convened at Toronto City Hall, during which Carla McKague, an electroshock survivor and legal representative for Mrs. T delivered remarks.³⁴⁰ This activist praxis demonstrated a mutually constitutive relationship of shared realizations (between patient activists and lawyers) as a means to address the case.³⁴¹ To comprehend the current or prospective impact of legal mobilization, particularly amidst evolving care paradigms such as the integration of technology such as AI and electronic records, it is essential to examine the preceding two decades of activist engagement. In my literature review, I examined the emergence of the recovery paradigm and the role of “peer workers” within it, particularly focusing on their function as a labour force. The utilization of peer workers primarily for role modeling has fostered a more limited scope of service user involvement in activism and justice mobilisation. In their capacity, peer workers guide patients towards attitudes and reactions that align with psychiatric governance systems vis a vis the adoption of recovery frameworks in these scenarios which encourage peer workers to employ concepts of hope and empowerment to motivate individuals to pursue conventional objectives of productivity.³⁴²

³³⁹ Please see Bonnie Burstow, “Conscientization: A new direction for ex-inmate education” (1989) 8:1 International Journal of Lifelong Education and, Pat McNenly “Committee on Shock treatment is biased say ex mental patients” *Toronto Star* (24 July 1984) A7.

³⁴⁰ For discussion on the Ontario Coalition meeting at City Hall in 1993 please see Don Weitz “Electroshock Must Be Banned Now: Strategies of Resistance” (Paper delivered at the PsychOut: A Conference for Organizing Resistance Against Psychiatry, OISE, Toronto, Ontario 2010) online:< at <https://perma.cc/WA7C-L7LV>> Pleasalso see: Other 16 -- No Title *The Globe and Mail* (Oct 20,1984) at 17.

³⁴¹ Don Weitz. Acceptance Speech for Award in Advocacy from the Mental Health Legal Committee delivered at the Centre for Addiction & Mental Health, Queen Street site, Toronto, April 27, 2007 online: <https://mindfreedom.org/kb/don-weitz-award-acceptance/> [<https://perma.cc/HU68-8PGL>].

³⁴² Aimee Sinclair, Sue Gillieatt, Christina Fernandes & Lyn Mahboub. “Inclusion as Assimilation, Integration, or Co-optation? A Post-Structural Analysis of Inclusion as Produced Through Mental Health Research on Peer Support” (2023) 33:6 Qualitative Health Research.

Having said this, Mad activist praxis continues to develop as a discipline of intellectual and theoretical work within Mad Studies to address the unresolved and ongoing harms at play in psychiatric sites.³⁴³ I employ this framework to better explore how legislation such as the *ECFAA*³⁴⁴ de-activates human rights discourse in psychiatric hospitals. In part, activist praxis is erased and rendered invisible by the ways service user knowledge and epistemology is resisted (in curriculum, committee work, focus groups etc.) and how individual narratives (stories, cases etc.) are sanitised and elevated over collective narratives.³⁴⁵

3.3 Mad /Service User Epistemology

Mad activist praxis and service user epistemology are intertwined given epistemology is a core tenet of Mad Studies' theoretical framework. The underpinning of this epistemological paradigm is centred on developing ideas and "collective action" that are avowedly "Mad" by placing service users, patient identity and self-determination at the centre of inquiry.³⁴⁶ As such, the focus of research, praxis and legal mobilisation³⁴⁷ is delineated to challenge prejudice and psychiatric hegemony, including colonial ways of knowing and /or abetting colonial methods of exploitation of psychiatric patients and service users.³⁴⁸

³⁴³ Alise de Bie. *Living A Mad Politics: Affirming Mad Onto-Ethico-Epistemologies Through Resonance, Resistance, and Relational Redress of Epistemic-Affective Harm* (PhD McMaster University 2019) [unpublished].

³⁴⁴ *Excellent Care for All Act*, *Supra* note 1.

³⁴⁵ Lucy Costa, Jijian Voronka, Danielle Landry, Jenna Reid, Becky Mcfarlane, David Reville, and Kathryn Church. "Recovering our stories": A small act of resistance." (2012) 6:1 *Studies in Social Justice*.

³⁴⁶ Jasna Russo. "The international foundations of Mad Studies: Knowledge generated in collective action." In Jasna Russo and Peter Beresford *The Routledge international handbook of mad studies*. (New York Routledge, 2021) at 19-29.

³⁴⁷ Please see: Mitchell Flagg "Foreword: Parkdale Community Legal Services: Twenty-Five Years of Poverty Law" (1997) 35 *Osgoode Hall L.J.*; Sheila Wildeman. "Agonizing Identity in Mental Health Law and Policy (Part II): A Political Taxonomy of Psychiatric Subjectification" (2015) 38:2 *Dal LJ* and Suzan E Fraser. "Representing People with Mental Health Problems: Understanding Your Client, Your Obligations and the Case: Sanism and the Legal Profession: Why Mad People Should Be Angry." In *Mental Health Issues and Criminal Law*. (Toronto, Law Society of Upper Canada, September 21, 2013) at tab 5.

³⁴⁸ Please see Ameil J. Joseph "Constituting "Lived Experience" Discourses in Mental Health: The Ethics of Racialized Identification/Representation and the Erasure of Intergeneration Colonial Violence" in Jijian Voronka

This field emerged in tandem with the larger tradition of Critical Disability Studies and alongside academic fields and liberation movements such as Women’s Studies, Black Studies and Queer Studies.³⁴⁹ Mad Studies praxis³⁵⁰ offers an important pedagogical and theoretical framework for influencing and enriching research methods. In contrast to the dominant perspectives of psychiatric medicine, a Mad Studies approach explores psychiatric disability through the lived experiences of individuals on the receiving end of mental health services, however they choose to identify or label themselves.³⁵¹ As an area of scholarship, it explores how dominant institutional discourses (in psychiatry and/or law) perpetuate sanism³⁵² and perpetuate beliefs that psychiatric disability begins with a presumption of individual deficit.³⁵³ The development of disability law and the promotion of disability law as an important and discrete area of law³⁵⁴ has aided in ameliorating perceptions of deficiency and disability prejudice and have mobilised initiatives and speciality clinics for people with disabilities.³⁵⁵

And Lucy Costa "Disordering social inclusion: Ethics, critiques, collaborations, futurities." (2019) 6 Special issue of Journal of Ethics in Mental Health. Please also see: Bhargavi V Davar,. "Shifting identities as reflective personal responses to political changes." in Jasna Russo, Peter Beresford eds. *The Routledge International Handbook of Mad Studies* (NewYork: Routledge, 2021). at 34-40.

³⁴⁹ Jasna Russo “The International Foundations of Mad Studies” in Jasna Russo and Peter Beresford. *The Routledge International Handbook of Mad Studies*. (Taylor and Francis, 2021).

³⁵⁰ Lucy Costa and Lori Ross, “Mad Studies Genealogy and Praxis” (October 2022) *International Mad Studies Journal*.

³⁵¹ Mark Castrodale, M.A. “Mad matters: a critical reader in Canadian mad studies”. (2015) 17:3 *Scandinavian Journal of Disability Research*, 284–246.

³⁵² Please see: Chapter 2 in Michael L Perlin *Advanced Introduction to Mental Health Law* (Northampton: Edward Elgar Publishing 2021).

³⁵³ For a discussion on the gap between many mental health service users and thinking on disability and impact of policies see: Peter Beresford, Rebecca Perring, Mary Nettle, and Jan Wallcraft. "From mental illness to a social model of madness and distress." (2016) online: <https://shapingourlives.org.uk/wp-content/uploads/2021/08/FROM-MENTAL-ILLNESS-PDF-2.pdf> [https://perma.cc/QB9P-G4E5] as well as Michael Stein et. al. *Mental Health, Legal Capacity, and Human Rights*: (Cambridge: Cambridge University Press, 2021) for a comprehensive, interdisciplinary analysis of pertinent issues in legal capacity in the Global North and the Global South with recommendations for reform.

³⁵⁴ Ann Lawson. “Disability Law As An Academic Discipline: Towards Cohesion and Mainstreaming?” (2020). 47:4 *Journal Of Law And Society*.

³⁵⁵ For example, ARCH Disability Law Centre in Toronto, Ontario and the Disability Law Clinic in British Columbia.

Vanhala notes that the 1970s were a time of mutually constitutive relationships in disability activism which pushed for and highlighted the need for physical disability rights and legal protections in Canada. This kind of relationship is exemplified by the shared consciousness between disability groups and others, including lawyers at that time (as mentioned above with the case of Mrs. T).³⁵⁶ Today however, discussions in the literature increasingly advocate for a more public-centric approach to access to justice³⁵⁷ it becomes imperative to discern the broader implications of this stance beyond conventional methodologies that merely solicit individual feedback within a system already constrained in delivering justice and currently grappling with overburdening. This prompts the question of what measures would effectively address access to justice issues. For genuine empowerment of the public through access to justice, it is essential to engage with a broad spectrum of practical obstacles to such access, and this requires a candid acknowledgment of societal factors based on identity that contribute to both inclusion and marginalization.³⁵⁸

In this study, I choose this methodological approach because I believe it is important for critical jurisprudence to consider service user epistemology. Although mental health law and service user epistemology follow divergent trajectories, both disciplines hold the potential to drive significant reform and enhance current practices, particularly in relation to improving dialogues concerning the duties of consultation. There exists the potential to shape the implications of mental health law in a manner similar to the beneficial influences of critical race

³⁵⁶ Lisa Vanhala, *Making Rights a Reality? Disability Rights Activists and Legal Mobilization* (New York: Cambridge University Press, 2010) and Laverne A., Jacobs, et al. *Law and Disability in Canada : Cases and Materials*. (Toronto: LexisNexis, 2021) at 105.

³⁵⁷ Trevor C Farrow, "What is access to justice." (2013) 51 Osgoode Hall LJ

³⁵⁸ Se-shauna Wheatle, "Access to Justice: From Judicial Empowerment to Public Empowerment." Bloomsbury, 2020. at 58.

theory, disability studies, and feminist theories on the legal framework. Service user epistemology, along with its theoretical framework, seeks to critically examine the consequences of marginalizing service user perspectives. This is particularly pertinent given the ways in which the law can be weaponized to the detriment of service users, despite statutory objectives that ostensibly emphasize "care" and "treatment."³⁵⁹ Further, standardizing legislation such as the *ECFAA*³⁶⁰ does not address the tension between the desire for more democratic "consultation" with patients and the command of scientific legitimacy.³⁶¹ This tension between these ideals of patient engagement and what service user stakeholders actually want holds significance given the various methodologies within healthcare, such as randomized control trials, which may not inherently serve the interests of service users or align with the perspectives of service user researchers.³⁶² Service users have rightfully scrutinized the underlying assumptions perpetuated by these systems, particularly regarding outcome measures typically devised by clinical researchers from their own perceived standpoint of desirability.³⁶³ Consequently, these omissions and exclusions are frequently perceived as instances of epistemic injustice.

³⁵⁹ Fleur Beaupert and Liz Brosnan. "Weaponizing absent knowledges: Countering the violence of mental health law." in Jasna Russo and Peter Beresford eds. *The Routledge international handbook of mad studies*. (New York: Routledge, 2021) at 119-131.

³⁶⁰ *Excellent Care for All Act*, *Supra* note 1.

³⁶¹ Katherine Boothe. "(Re)defining Legitimacy in Canadian Drug Assessment Policy? Comparing Ideas over Time." (2021) 16:4 *Health economics, policy and law*.

³⁶² For an example of this, please see the current debates debunking the serotonin "chemical imbalance" theories of the brain: Joanna Moncrieff et. al. "The serotonin theory of depression: a systematic umbrella review of the evidence" (2022) *Mol Psychiatry*.

³⁶³ Diana Rose, "Service user produced knowledge" (2008) 17:5 *Journal of Mental Health*.

3.4 Epistemic injustice

The term "epistemic injustice," first coined by Fricker, refers to the unfair dismissal or devaluation of someone's knowledge or perspective based on their identity.³⁶⁴ A service user and Mad epistemological analysis of epistemic injustice addresses not merely the silencing of individuals with psychiatric disabilities but also the microaggressions and critiques that sustain the marginalization of the contributions, knowledge, and scholarship of the service user community, particularly when these contributions diverge from privileging medical knowledge as the sole authoritative epistemic framework. For instance, psychiatrists Kious et al. exemplify this issue by contending that psychiatrists need not alter their practices in response to allegations of epistemic unfairness within the field. They argue that such claims distort routine psychiatric practices, rest on irrational premises, or emphasize concerns that are already addressed by existing standards.³⁶⁵ However, there is a notable disparity in their approach to addressing epistemic injustice concerning gender or race compared to psychiatric disability.³⁶⁶ While they concede the importance of challenging bias concerning gender and race, they appear to contend that analogous epistemological reflections do not apply to concerns of psychiatric disability or, in legal terms, what might be termed "historical disadvantage."³⁶⁷

Kurs and Grinshpoon affirm that individuals with mental health issues often report experiences of not being heard, taken seriously, or treated fairly due to their psychiatric

³⁶⁴ Miranda Fricker, *Epistemic Injustice : Power and the Ethics of Knowing* (Oxford ; Oxford University Press, 2007).

³⁶⁵ Brent Kious, Benjamin Lewis, & Scott Kim Epistemic injustice and the psychiatrist (2023) 53:1 Psychological Medicine, at 4 .

³⁶⁶ Although the journal *Psychological Medicine* did not publish a rebuttal written by service users themselves, they did publish a rebuttal as a follow up response to Brent Kious, Benjamin Lewis, & Scott Kim's critique of "Epistemic Injustice" by Dr. Aftab. Please see: Awais Aftab. "Epistemic justice is an essential component of good psychiatric care" (2023) Psychological Medicine.

³⁶⁷ Please see: Michael L Perlin, "Sanism and the Law" (2013) 15:10 American Medical Assoc J Ethics at 878.

conditions.³⁶⁸ And despite arguments regarding professional “standards”, this phenomenon became evident during the COVID-19 pandemic, where adherence to standards seemed to diminish.³⁶⁹ Numerous instances and discussions of epistemic injustice exist.³⁷⁰ For example, an incident at the Centre for Addiction and Mental Health in April 2006 serves as a notable case, wherein allegations of misappropriation of patients' funds prompted a police investigation:

There is an ongoing police investigation into the embezzlement by an employee of CAMH who works in the cash office,” a source close to the investigation said. Apparently hundreds of thousands of dollars may have been stolen over many years from our clients. You have to wonder how many (patients) were found not capable to manage their funds once they expressed a concern that the cash office was stealing from them.³⁷¹ This incident underscores the nuanced nature of epistemic injustice, which centres on the credibility of individuals as knowers. Such transgressions, in this instance constituting a crime, are often framed as aspects of the "stigma" faced by psychiatric patients. However, attributing these injustices to "stigma" alone is an overly facile explanation.³⁷²

Thus, my point concerning epistemic injustice in the context of my study is as follows: The establishment of PDoVs may inadequately address epistemic injustice, seemingly prioritizing the regulation of values over the recognition and confrontation of sanist and ableist practices. This highlights the necessity for a proactive approach to addressing the structural

³⁶⁸ Rena Kurs & Alexander Grinshpoon “Vulnerability of Individuals With Mental Disorders to Epistemic Injustice in Both Clinical and Social Domains” (2018) 28:4 Ethics & Behavior.

³⁶⁹ Ruby Dhand, et al. “Litigating in the Time of Coronavirus: Mental Health Tribunals’ Response to COVID-19.” 2020 37: 1 The Windsor Yearbook of Access to Justice.

³⁷⁰ Please see: Lauren Munro, Lucy Costa. (Accepted). Centring Madness in medical education: Storying a psychiatry residency education project. In A. Davies, L. Spring, & M. Castrodale (Eds.). *The Surveillance and Regulation of Madness in Educational Settings: Critical Pedagogy and Mad Futurities*. (Palgrave Macmillian) ; .Michelle Colder Carras et. al.”Strengthening Review and Publication of Participatory Mental Health Research to Promote Empowerment and Prevent Co-optation” (2023) Feb 1:74:2 Psychiatr Serv.; Celestin Okoroji, et al. “Epistemic Injustice and Mental Health Research: A Pragmatic Approach to Working with Lived Experience Expertise” (March 28, 2023) 14 Frontiers in Psychiatry.

³⁷¹ Kevin Connor, “Cops Probe Theft Of Patients' Funds Hundreds Of Thousands Of Dollars Feared Missing At Centre For Addiction-Mental Health” *Toronto Sun* (7 May 2006).

³⁷² Imogen Tyler, *Stigma: The Machinery of Inequality* (London: Zed, 2020).

inequalities embedded within the system.³⁷³ Given these structural inequalities, ways of knowing and epistemologies are not mere epiphenomena but rather constitute fundamental components of social institutions and actions.³⁷⁴ And hegemonic epistemologies are not found separate from politics, but rather are woven into and contribute to constructs of the political.³⁷⁵ The maintaining social inequality relies on tactics of epistemic injustice that together uphold epistemic oppression and historical disadvantage.

3.5 Sanism

Distinguished from stigma, sanism is a deeply entrenched structural form of discrimination and a significant component of epistemic injustice. Ableism and sanism while similar are forms of discrimination targeting different groups. Ableism involves prejudice against people with physical, intellectual, developmental, and sensory disabilities, creating barriers/ disadvantage. Sanism³⁷⁶ targets individuals with psychiatric disabilities, embedding prejudice in societal, legal, and institutional practices.

Sanism expresses a concept that stigma and ableism discourses fail to fully realize; that the experiences of inequality, microaggressions and structural embedded disadvantage within various institutions is unique to psychiatric disability and experiences of psychiatric distress. Sanism has since been extensively discussed in Mad Studies literature, as well as highlighting

³⁷³ Gillian Mulvale, et al. “Co-creating a new Charter for equitable and inclusive co-creation: insights from an international forum of academic and lived experience experts”. (2024) *BMJ Open*.

³⁷⁴ Patricia Hill Collins, “Intersectionality and Epistemic Injustice.” in Ian James Kidd ; José Medina ; Gaile Pohlhaus, Jr *The Routledge Handbook of Epistemic Injustice*, 1st ed., (Oxford: Routledge, 2017) at 118.

³⁷⁵ *Ibid* at 118.

³⁷⁶ The term “sanism” was introduced in the legal field by Morton Birnbaum in 1960. See: Morton Birnbaum, “The Right To Treatment.” (1960) 46:5 *American Bar Association Journal*.

the intersection of race and the theorization of more specifically anti-Black sanism.³⁷⁷ Evidence of emergent dialogues on sanism can be found on social media platforms such as Facebook and Twitter with dedicated accounts to track and share experiences of sanism³⁷⁸ as well as organizations such as the Coalition against sanist attitudes (CASA)³⁷⁹ While psychiatric survivor Judi Chamberlin described the prejudicial impacts of, in her terms, “mentalism” (or sane chauvinism) towards psychiatric patients years ago,³⁸⁰ it was lawyer Michael Perlin who began talking about sanism more deeply as an issue in the courts given the problem of pretextual decision-making when judges and juries form their judgements based on their own ideals or self-interests as opposed to the actual law.³⁸¹ Some activists and academics within Mad Studies question the adequacy of sanism as a framework for addressing all the structural impositions of psychiatry. Cresswell and Spandler pose the question:

Is Mad experience completely reducible to sanism? These are questions about those that are external to the ‘system’, for example, people who are ‘Mad’ but not subjected to sanism. Second, what about the internal differentiation of madness? Are there any differences within and between those designated Mad? Is every individual on the receiving end of ‘diagnoses and treatment’ subject to sanism and therefore a subject of Mad Studies?³⁸²

Others have expanded on these questions by asserting that “sanism” is not the same for everyone and that there different “embodied experiences of sanism” that intersect with class, sexuality,

³⁷⁷ Sonia Meerai, Idil Abdillahi, and Jennifer Poole, "An introduction to anti-Black sanism." (2016) 5:3 Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice

³⁷⁸ For Facebook please see: <https://perma.cc/F58X-ZWKF> for Twitter please see: <https://perma.cc/T8VQ-DHXX>.

³⁷⁹ Jennifer M. Poole, Tania Jivraj, Araxi Arslanian, Kristen Bellows, Sheila Chiasson, Husnia Hakimy, Jessica Pasini, and Jenna Reid, “Sanism, ‘Mental Health’, and Social Work/Education: a review and call to action” (2012) 1 Intersectionalities: A Global Journal of social Work Analysis, Research, Polity, and Practice.

³⁸⁰ Judi Chamberlin The Ex-Patients’ Movement: Where We’ve Been and Where We’re Going. (1990) 11:3:4 The Journal of Mind and Behavior.

³⁸¹ Michael L Perlin, “A Half-Wrecked Prejudice Leaped Forth’: Sanism, Pretextuality, and Why and How Mental Disability Law Developed As It Did,” (1999)10:3 J. Contemp Legal Issues.

³⁸² Mark Cresswell and Helen Spandler, “Solidarities and Tensions in Mental Health Politics: Mad Studies and Psychopolitics.” (2016) 4.3 Critical and radical social work.

gender and religion.³⁸³ According to Meerai et al., we need to decentre whiteness in the mental health field as well as in the ex-patient, survivor, disability, and mad movement and instead discuss anti-Black sanism as a framework that names the injustice of historical discrimination and the ongoing overrepresentation of people who identify as Black or African in the mental health system.³⁸⁴ These criticisms are shared by others as well who emphasize that:

the mental health system does not consider the epistemological experiences of Black men within the decision making process or the importance of Afrocentric models to redress the power of White psychiatry.³⁸⁵

If this is the case in psychiatry, it undoubtedly remains a challenge in law. For instance, implicit bias was recognized as part of the scope negotiated by parties before the inquest of Andrew Loku in 2017 commenced, whereas racism was not.³⁸⁶ Tools such as the use of “Impact of Race and Culture Assessments” give courts the information they need to know about the impacts of systemic anti-Black racism on people of African descent and how that experience has influenced the circumstances of the offence and the court's decision.³⁸⁷ This however, needs to be broadly integrated into psychiatric hospital practices or their values more explicitly given report of increased coercion for racialised individuals.³⁸⁸ Moreover, expanding upon the existing initiatives within many hospitals that address Indigenous health and the intergenerational impacts

³⁸³ Sonia Meerai, Idil Abdillahi, and Jennifer Poole, *Supra* note 376.

³⁸⁴ *Ibid* at 23.

³⁸⁵ Colin King and Tamar Jeynes, “Whiteness, Madness, and Reform of the Mental Health Act” (June 2021) 8:6 *The Lancet Psychiatry* at 461.

³⁸⁶ Wendy Gilles “Final witness prompts debate over racism at Andrew Loku inquest” (June 20 2017) online: *Toronto Star* [<https://perma.cc/2HS6-W46W>].

³⁸⁷ Marie C Dugas, “Committing to justice: The case for impact of race and culture assessments in sentencing African Canadian offenders” (Winter 2020) 43 *Dalhousie LJ* at 103.

³⁸⁸ In approximately late 2018 and onward CAMH data discovered that rates of restraint use were 44 per cent higher among Black patients than among white patients. As a result, the Fair & Just CAMH was launched in 2019 with a commitment to advance diversity, equity and inclusion. They produced a report “Dismantling Anti-Black Racism, a Strategy of Fair & Just CAMH” to outline priority areas that aimed to decrease anti-Black racism at CAMH by 2022. online: <https://www.camh.ca/-/media/files/camh-dismantling-anti-black-racism-pdf.pdf> [<https://perma.cc/CTB4-A85D>].

of colonialism, as Dwornik observes, there is a compelling opportunity to place sanism, and colonialism into a meaningful dialogue with one another.³⁸⁹

Although there are occasional references to racism and gender there is no inherent limitation preventing a broader analysis. Indeed, such an expansion of focus begins to emerge as societal influences shape institutional practices.³⁹⁰ The implication for this is best articulated by one individual who describes being diagnosed with a psychiatric condition at 16 years old and undergoing treatment for six years. It was not until graduate school that they discovered the Mad movement, which gave them the language to understand their experiences beyond psychiatry. They wish they had known about the Mad movement earlier, particularly during their undergraduate studies, to discuss sanism alongside other forms of discrimination they were feeling.³⁹¹ As LeBlanc and Kinsella note, the term "sanism" performs a crucial cognitive and discursive function by illuminating the hermeneutical obscurity that hinder service users from fully comprehending the injustices they endure under the guise of healthcare, and public and personal safety.³⁹²

3.6 Legislation: What does Mad Studies have to do with it?

Mad Studies has emerged as a new and important field of inquiry.³⁹³ Applying Mad Studies to law and legislation, including the *ECFAA*³⁹⁴, entails integrating the "lived experience" of

³⁸⁹ Ania Dwornik, "The Interface of Mad Studies and Indigenous Ways of Knowing: Innovation, Co-Creation, and Decolonization" (2022) 22:2 Critical social work.

³⁹⁰ Expanding the understanding of structural sanism and other prejudices is entirely achievable. For instance, during a curriculum review meeting on Friday, May 3, 2024, a psychiatry resident included a segment on anti-Black sanism in their presentation on Equity and Diversity. This example underscores the feasibility of integrating such analysis into these disciplines, highlighting its practicality and potential impact.

³⁹¹ P. M. Wolframe, "The madwoman in the academy, or, revealing the invisible straightjacket: Theorizing and teaching sanism and sane privilege." (2013a) 33:1 Disability Studies Quarterly.

³⁹² Stephanie LeBlanc and Elizabeth Anne Kinsella, "Toward Epistemic Justice: A Critically Reflexive Examination of 'Sanism' and Implications for Knowledge Generation." (2016) 10:1 Studies in Social Justice.

³⁹³ Alex Gillis, *Supra* note 53.

individuals with psychiatric disabilities who receive services. Tackling challenges related to improving healthcare (for the individual) must take into consideration, a collective history and epistemology of service users, the activism that contributed to discussions about rights which existed prior to the *ECFAA*³⁹⁵, the epistemic injustices in need of reparations, and the sanism that is prevalent in mental health courts and tribunals.

It is precisely collective history that presents challenges in sites (such as hospitals) where psychocentrism³⁹⁶ is dominant and where different knowledge and subjectivities are frequently resisted and/or erased.³⁹⁷ Frazer-Carroll reiterates this point:

From a present-day perspective, it is curious that the histories of these political movements have been erased, while the movements have left little imprint on the ways that mental health is approached and understood today. In the current climate, we still largely discuss mental health in terms of individual identity (something we are) and property ownership (something we have) - rather than as a form of collective oppression (something that is done to us).³⁹⁸

Applying Mad Studies as methodology, therefore, assesses how a collective history of Mad people and psychiatric disability work in concert with other intersectional considerations (race, sexual orientation, gender identity, class, age, faith and belief etc.) as well as international dialogues such as the work of the United Nations Convention on the Rights of Persons with

³⁹⁴ *Excellent Care for All Act*, *Supra* note 1.

³⁹⁵ *Ibid.*

³⁹⁶ Rimke refers to psychocentrism as the view that all human problems are innate pathologies of the individual mind and/or body, with the individual held responsible for health and illness, success and failure. Please see: Heidi Rimke. *Governing citizens through self-help literature* (2000) 14:1 *Cultural Studies*.

³⁹⁷ Please see: Geoffrey Reaume, "Ancient History" *The Relevance Of The Past To The Present In Ontario's Psychiatric History* *Honouring The Past, Shaping The Future: 25 Years Of Progress In Mental Health Advocacy And Rights Protection*. (Queens Printer for Ontario: Psychiatric Patient Advocate Office, 2008) at 12. Here Reaume discusses the problem with a 2006 hearing before the Ontario Human Rights Tribunal in *Braithwaite and Illingworth v. Attorney General for Ontario and Chief Coroner of Ontario*. In this case, the lawyer for the provincial government made the claim that listening to historical accounts of abuse of the insane asylum inmates from 19th and 20th century was "ancient history."

³⁹⁸ Micha Frazer-Carroll, *Mad World: The Politics of Mental Health* (London: Pluto Press 2023) at 6.

Disabilities ("UNCRPD") to make sense of what “excellent care” means and what patient values include or exclude drawing from local level knowledge and international records. For example, the UNCRPD was the outcome of significant effort by cross-disability rights organizations who advocated for a disability-specific convention and participated in the debates held during drafting.³⁹⁹ As a result, the work of, for instance, the United Nations Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar who visited Canada and Toronto⁴⁰⁰ in 2019, should feature more robustly in how standards and human rights are addressed. Yet, there is no evidence that any of the recommendations of the *Report of the Special Rapporteur on the Rights of Persons with Disabilities*⁴⁰¹ have ever been implemented, let alone considered at a hospital level despite the intensified significance of human rights for people with psychiatric disabilities in international law. A Mad Studies theoretical approach looks at the extent to which international human rights legislation is followed in both implementation and interpretation with special attention to human rights infractions, human rights abuses and questions as required about reparations.⁴⁰² In many ways, the examination of the *ECFAA* and PDoVs is a theoretical look at what tenets of patient voice are there, and which ones are not and why. As Rose aptly puts it in regards to service user epistemology:

³⁹⁹ Lisa Vanhala, *Supra* note 196 at 28.

⁴⁰⁰ In March 2019, a representative of the United Nations High Commissioner for Human Rights reached out to me to set up a meeting with Special Rapporteur, Ms. Catalina Devandas-Aguilar with myself at the Empowerment Council as well as CAMH. Email exchange between Alina Grigoras Associate Human Rights Officer Office of the United Nations High Commissioner for Human Rights and Lucy Costa March 12, 2019 11:49 AM.

⁴⁰¹ United Nations Human Rights Council. *Report of the Special Rapporteur on the Rights of Persons with Disabilities on her visit to Canada: comments by the State* (March 2020). Online: United Nations Digital Library <<https://digitallibrary.un.org/record/3848188?ln=en>> [<https://perma.cc/2AUU-5MZH>]

⁴⁰² Fleur Beaupert, Liz Brosnan *Supra* note 359.

Although it may appear that people are listening now, the legacy of that silencing persists and some will go to any lengths to keep this legacy going, sometimes at any cost, which is not to say that nothing has changed. It is to say the change has been a struggle.⁴⁰³

Improving the quality of life that service users experience in daily life is unproductive in the absence of the established theoretical work of Mad identified people who have been examining the nature of psychiatric practices, context, etc. for years; this is true of both mainstream clinical research translation itself and efforts to change patient realities, through the psychiatrist visit.⁴⁰⁴

While, PDoVS and patient representation conveys symbolic⁴⁰⁵ attention to the centrality of patient involvement in healthcare, it has not done so in a vacuum. As public hospitals have been increasingly corporatized and animate “business-like” practices with the direct involvement of corporate/private partners such as banks etc.⁴⁰⁶ new vocabularies that promote patient coproduction, collaboration and shared decision-making have replaced and depoliticised a collective voice and service user epistemology.

3.7 The Outsider Within - Standpoint

I engage with Mad Studies theory and critical analysis to examine how discourses of patient engagement, the *ECFAA*,⁴⁰⁷ and hospital values statements represent a newly constructed vocabulary shaping patient voice and inevitably rights in light of the erosion of independent advocacy. As I mention in Chapter 1 the struggle for rights recognition for service users draws from this long lineage of activism and advocacy by people who were instrumental in shaping the

⁴⁰³ Diana Susan Rose. *Mad Knowledges and User-Led Research*. (Switzerland: Palgrave Macmillan, 2022) at 8.

⁴⁰⁴ *Ibid* Rose at 117.

⁴⁰⁵ Paula Rowland and Arno K. Kumagai. *Supra* note 127 at 871.

⁴⁰⁶ Jamie Brownlee, Chris Hurl, and Kevin Walby. *Corporatizing Canada: Making Business Out of Public Service*, (Toronto: Between the Lines, 2018).

⁴⁰⁷ *Excellent Care for All Act*, *Supra* note 1.

counter-discourses which fostered consciousness raising necessary to claim rights in the first place. To answer my research questions, along with the epistemological work of Mad Studies, I also use Standpoint theory as a means to draw from my social location and expand discussion about the advocacy landscape for service users as a tidal wave of patient engagement discourse has arisen over the last twenty years.

In order to inform my research work I drew from the works of feminist philosopher Sandra Harding⁴⁰⁸ who sees standpoint as integral to scientific and political discourse and more importantly, as a means to transform oppressed individuals as collective subjects of research and towards agency, as opposed to being observed, named, and managed by others.⁴⁰⁹ Dorothy Smith is valuable in her descriptions of power relations as standpoints of experience from the everyday world, abstracted from particular settings and relationships and as forms of communication that are distinctively mediated by texts from the position of institutional dominant ruling assemblages⁴¹⁰. Standpoint theory initially emerged⁴¹¹ in the 1970s and 1980s as a feminist critical theory about the assemblages between knowledge production and practices of power⁴¹². Standpoint theorists such as Sandra Harding emphasized the importance of social

⁴⁰⁸ Sandra Harding, "Introduction: Standpoint Theory as a Site of Political, Philosophic, and Scientific Debate" in Sandra Harding ed. *The Feminist Standpoint Reader*. (New York: Routledge 2004).

⁴⁰⁹ *Ibid* Harding at 3.

⁴¹⁰ Dorothy Smith, *Texts, Facts and Femininity: Exploring the Relations of Ruling*. (London: Routledge 1990) at 2.

⁴¹¹ I draw from primarily feminist standpoint theory although Georg Wilhelm Friedrich Hegel, Karl Marx György Lukács had each theorised early ideas of standpoint with respect to master/slave dialectic and the development of "self-consciousness" (Hegel); class consciousness and standpoint of the proletariat ((Marx and Lukács).

⁴¹² Please see: Dorothy Smith, *The Everyday World as Problematic: a Feminist Sociology*. (Toronto: University of Toronto Press, 1998); Nancy Harstock, "The Feminist Standpoint" in Sandra Harding and Merrill B. Hintikka eds. *Discovering Reality* (Holland; Boston; London : D. Reidel Publishing Company, 1983); Patricia Hill Collins, *Black Feminist Thought* (New York: Routledge 2000).

location given that those with cultural capital at the top of the economic hierarchy have the power to define and legitimate certain ontological experiences over others⁴¹³. To clarify further:

Standpoint is not simply an interested position (interpreted as bias) but is interested in the sense of being engaged. It is true that a desire to conceal real social relations can contribute to an obscurantist account, and it is also true that the ruling gender and class have material interests in deception. A standpoint, however, carries with it the contention that there are some perspectives on society from which, however, well-intentioned one may be the real relations of humans with each other and with the natural world are not visible.⁴¹⁴

I am aware that to do justice to the stories, activism, and labours of people with psychiatric disabilities turning to a standpoint theoretical framework enables me to ground this work in Mad Studies genealogy, and further contribute to current scholarship and ethical questions about, inclusion projects, raised by Mad people themselves.⁴¹⁵ However, even though I use standpoint theory in my thesis, I do not promote any one perspective or identity related to madness or illness as being more important than others in this study or in Mad Studies; no singular identity category can comprehensively encapsulate the diverse array of intersecting experiences encompassing psychiatric disability, racism, Indigeneity, sexual orientation, gender, or class. Instead, I draw from Russo and Sweeney when they note, that standpoints are informed by our own research practices, by our activism in the international movement of psychiatric survivors, and by our personal experiences.⁴¹⁶

⁴¹³ Harding *Supra* note 407.

⁴¹⁴ Nancy C. M. Hartsock, "The Feminist Standpoint: Developing the Ground for A Specifically Feminist Historical Materialism" in Sandra G, Harding, *The Feminist Standpoint Theory Reader : Intellectual and Political Controversies*. (New York: Routledge 2004) at 159.

⁴¹⁵ Jijian Voronka and Lucy Costa, "Disordering social inclusion: Ethics, critiques, collaborations, futurities." (2019) 6 Special issue of *Journal of Ethics in Mental Health*.

⁴¹⁶ Jasna Russo and Jan Wallcraft, *Supra* note 256 at 213.

Assuming the role of a mental health service user researcher often entails navigating a "double identity" or being labeled as "the outsider within." Being situated in this dual capacity, both as an insider (a researcher) and an outsider (an individual with lived experience working as an advocate in a service user organization), enables me to leverage this unique perspective in conducting my research. This dual identity allows me to analyze and scrutinize the intricate implications of the study, drawing upon my frontline experience and day-to-day work in a psychiatric facility, as well as my immersion in service user/Mad scholarship. Navigating these roles can prove challenging, as highlighted in service user literature. Scholars have extensively deliberated on the intricacies of conducting research while actively participating within such systems, illustrating the complex and ambiguous nature inherent in this "betwixt and between" position.⁴¹⁷ In this study, I endeavoured to unpack the familiar maxim, "nothing about us, without us," by probing the implications when the essence of "us" becomes entwined within the very fabric of institutions. I sought to demonstrate the nuanced meaning behind these overtures of inclusion, extended to service users, beckoning their complicity within the corridors of institutional power, in advisories and committee work.

My strongest introduction to learning about advocacy was in the late nineties where I attended a few meetings of the Ontario Advocacy Coalition⁴¹⁸. This Coalition had been instrumental in contributing to the development of the *Ontario Advocacy Act*.⁴¹⁹ The meeting I

⁴¹⁷ For further reading please see: Rose *Supra* note 402; Alison Faulkner, and Rose Thompson. "Uncovering the Emotional Labour of Involvement and Co-Production in Mental Health Research." (2023) 38:4 Disability & Society; Jasna Russo. "Survivor-Controlled Research: A New Foundation for Thinking about Psychiatry and Mental Health." (2012) 13:1 Forum: Qualitative Social Research; Angela Sweeney and Peter Beresford. "Who gets to study whom: survivor research and peer review processes" (2020) 35:7 Disability & Society.

⁴¹⁸ For a history of the Advocacy Coalition please see: Ernie Lightman and Uri Aviram. "Too Much, Too Late: The Advocacy Act in Ontario" (2000) 22.1 Law & Policy.

⁴¹⁹ Gail Swainson, "Protesters seek agency to protect disabled, elderly" *Toronto Star* (Sep 01 1990) at A6.

attended was chaired by Canadian Association for Community Living lawyer Orville Endicott and the coalition's aspiration was to create a system of social advocacy services for vulnerable adults in the province.⁴²⁰ In 1995, following the election of Mike Harris as Ontario Premier, the *Ontario Advocacy Act* was promptly repealed. In the wake of this repeal, the Coalition found itself at a crossroads, deliberating its subsequent actions. It was during this period that I gained insight into advocacy, legal matters, political strategy, and the complexities of conflict of interest.

In 1999, I secured a Trillium Foundation funded two-year contract position with the Queen Street Patient Council.⁴²¹ This council, the second of its kind within an Ontario psychiatric hospital, was established following the pioneering model initiated at the former Kingston Psychiatric Hospital.⁴²² Upon my initial appointment to engage in advocacy on behalf of the Queen Street Patients' Council, the hiring committee comprised one staff member, Erick Fabris⁴²³ (a former hospital detainee subjected to involuntary restraint) and three other men identifying as "survivors." The bulk of my contract work consisted of educating police officers at C.O. Bick College following the inquest recommendations in the police shooting of Edmond Yu.⁴²⁴ I was also responsible for creating some curriculum for rights education concerning the *Ontario Mental Health Act*⁴²⁵ and the emergent recovery literature. After that contract ended, I worked in a local community healthcare centre developing a youth engagement project on

⁴²⁰ Lightman, and Uri *Supra* note 417 at 26.

⁴²¹ The Queen Street Patients Council (incorporated in 1995) had a meagre operating budget of \$58,000.

⁴²² Theresa Claxton, *Supra* note 156 at 83.

⁴²³ The Queen Street Patient's Council had two part-time contract staff. Jennifer Chambers and Erick Fabris. Fabris served as my main point of contact and was the lead at the Queen Street Patients Council. Fabris, along with volunteers, assumed the majority of the workload and responsibility for maintaining the organizational duties, the website, the membership, contact list, the organisation of Board meetings, committee work etc.

⁴²⁴ Please see: Sue McCluskey "Yu Inquest Delivers Verdict." (1999) 2:3 Cross Currents (Toronto) online: <https://falconers.ca/casestudy/edmond-yu-inquest> [4 <https://perma.cc/XXN6-NXP5>]

⁴²⁵ *Ontario Mental Health Act*, *Supra* note 286.

healthcare rights. I was later rehired in 2004 to work at the Empowerment Council (the successor to the Patient Council).

At the Empowerment Council my employment has encompassed systemic and legal advocacy, research, supervision of EC part-time staff, student placements, and more recently, education, which continues to comprise the majority of my professional portfolio as I write this thesis. I have been deeply immersed in both academic and community work in the mental health sector for many years. I have offered character references in Ontario Review Board (ORB) hearings, as well speaking on behalf of clients at ORB tribunals. Additionally, I underwent cross-examination for a constitutional challenge in 2012 and aided patients in participating in a class action suit against Eli Lilly Canada Inc. in 2010. As Deputy Executive Director of the Empowerment Council, I have also developed curriculum and taught psychiatry residents at the University of Toronto. I have supervised university students as well as hired individuals to work on projects for my office. I have intervened in hostile and discriminatory union initiatives and addressed problematic union projects⁴²⁶. I have sat on too many internal CAMH committees to count and have conducted hundreds of focus groups with service users internally at CAMH, on behalf of the Empowerment Council. Additionally, I have worked in partnership with the Ontario Human Rights Commission, Legal Aid Ontario, Legal Clinics, Government and many hospital or Ministry consultants. I have involved in numerous research projects through the Canadian Institute of Health Research (CIHR) or the Social Sciences and Humanities Research Council (SSHRC). Throughout my career, I have encountered both extremely unpleasant staff and service users, as well as tremendously committed staff members and profoundly moving, intelligent, and

⁴²⁶ Please see: Lucy Costa, “OPSEU Delivers on Promise to Release New Ad For the Psychiatric Survivor and Consumer Community” online at <https://empowermentcouncil.ca/wp-content/uploads/2021/02/EC-Summer-2010-Report.pdf> [https://perma.cc/FWC6-39H2] at 3.

creative service users who have persevered through the most stressful and severe circumstances. Despite the intricate nature of this field and encountering numerous ethically challenging situations, there has been a discernible shift in access to legal services and advocacy over the past decade.

I began this chapter with a discussion of Mad Studies, standpoint theory and with the contention that certain realities tend to be more visible from the perspective of the subordinated when space is permitted. There is substantial literature from service users/survivors that have commented on the myth of neutrality in science and mental health research.⁴²⁷ Standpoint does not merely exist to create dualism between that which is considered “situated knowledge” and that which is “scientific” but instead, its triumph is in establishing and highlighting areas of tension with hegemonic theories of biomedicine and practises that are uncritically examined and accepted as truth. Patricia Hill Collins has eloquently articulated how marginalized groups are often discredited as epistemic agents and have their credibility undermined. This discrediting occurs by portraying identity politics as inferior and standpoint epistemology as limited and biased.⁴²⁸

Standpoint asserts the right of individuals to be equal epistemic agents in interpreting their own realities within interpretive communities. These theories emphasize the importance of considering the social positioning of agents when analyzing their perspectives.⁴²⁹ “Mad” standpoint offers critical analyses on ways of knowing in respect to psychiatric experiences, or

⁴²⁷ Please see for example: Jasna Russo “Survivor-Controlled Research: A New Foundation for Thinking about Psychiatry and Mental Health”. (2012) 13:1 Forum Qualitative Sozialforschung and Peter Beresford, *It's Our Lives: A Short Theory of Knowledge, Distance and Experience*. (London: Citizen Press, 2003) for discussion on research approaches that favour closeness to the subject as opposed to "scientific distance."

⁴²⁸ Patricia Hill Collins, *Supra* note 373 at 119.

⁴²⁹ *Ibid.*

extreme states and presents potential for reconfiguring methods that are more democratic and less repressive⁴³⁰. These standpoint narratives assist in developing better outcomes and theoretical frameworks not because they assume an essentialist truth but rather because, in contrast to modern Western science, they arise from marginalised subjectivities. One such concrete example of embodied and situated knowledge working in this way was the work of the AIDS movement at the height of the AIDS crisis that had people with AIDS organise for advancing clinical trials and risking their lives for the advancement of science.⁴³¹

My standpoint has permitted me to be well-positioned to see that there are complex forms of injustice that we fail to consider if we only understand justice as amelioration through the courts or tribunals: this is my empirical claim. A thorough analysis of justice must take into account the inequities that exist for psychiatric service users and develop the conceptual innovations required to map them out. I am suggesting that people aligned with these methodologies and praxis continue to do precisely that. This thesis marshals this argument forward, adds to previous research I and others have conducted looking at narratives and documentation practices in hospital sites⁴³² and confronts the assumption that there is an impartiality to practices of documenting, consulting, and engagement. Finally, by utilizing Mad Studies and standpoint, this thesis exercises reflexivity to (re) emphasize the value of advancing knowledge-production by service users while still juggling the tension between “identity”(i.e. that of a service user, Mad person etc.) as a marker of essentialist truth with the more urgent

⁴³⁰ Alison Faulkner, Phil Thomas, “User-led research and evidence-based medicine” (2002) 180:1 British Journal of Psychiatry.

⁴³¹ Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge*, (Berkeley: University of California Press 1996) at 236-265.

⁴³² Andrea Daley, Lucy Costa, and Lori Ross, “(W) righting Women: Constructions of Gender, Sexuality and Race in the Psychiatric Chart” (2012) 14:8 Culture, health & sexuality.

requirement to look at the conflicts and intersections between visible and invisible discourses at play in institutional sites.

CHAPTER 4 THE RESEARCH PATH

*... the research design process in qualitative research begins with philosophical assumptions that the inquirers make in deciding to undertake a qualitative study. In addition, researchers bring their own worldviews, paradigms, or sets of beliefs to the research project.*⁴³³

My study examined the role of the *Excellent Care for All Act (ECFAA)* and specifically the Patient Declaration of Values (PDoV) statements⁴³⁴ with a view to demonstrating how language performs and shapes the ways in which we are contemporarily understanding constructions of patient experience in psychiatric hospitals with a specific emphasis on human rights. In this chapter, I break down how I went about collecting, coding, and analyzing the selected hospitals for this study. First, I will discuss why I chose thematic analysis as the method, covering its main tenets and whether it is a good fit for examining PDoVs. Following this, I will elaborate on the research design, providing information into the methods employed for data collection and analysis, including Phase 1 of manual coding and Phase 2 utilizing NVivo for coding purposes. Through this lens of thematic analysis I aimed to illustrate the discourses embedded in PDoVs. The direction of my research path is guided by the following research questions:

1. What discursive themes appear across the PDoVs in the nine hospitals?⁴³⁵
2. How do the themes in the PDoVs indicate a focus on human rights, the patient advocate office, or other mechanisms for rights protection?

⁴³³ John Creswell, *Qualitative inquiry and research design: Choosing among five traditions*. 2nd edition (Thousand Oaks, CA: Sage 2013)

⁴³⁴ Ontario Ministry of Health and Long Term Care, *Guidance Document for the Declaration of Values*, *Supra* note 12.

⁴³⁵ These nine facilities included: The Royal, St. Joseph's Healthcare, Providence Care Hospital, Parkwood Institute, Waypoint Centre for Mental Health, Southwest Centre for Forensic Mental Health Care, St. Joseph's Health Care Group, The Centre for Addiction and Mental Health and Ontario Shores Centre for Mental Health Sciences.

3. How do discursive themes and evidence related to patient voice, identity and engagement emerge from the PDoVs in the nine hospitals?

4.1 Thematic Analysis

Thematic analysis stands as a versatile research tool used by numerous researchers given it facilitates nuanced exploration and understanding of various aspects of a research question including the social context, political ideologies, and the economic trends etc. related to the research questions. Boyatzis emphasizes that thematic analysis serves qualitative researchers and social scientists by enabling them to elucidate social situations, cultural practices, individual experiences, and various other aspects.⁴³⁶ Moreover, he suggests that this method facilitates interpretive and positivist researchers in comprehending and expanding upon each other's observations. Thematic analysis provides positivist scientists with a foundation for conducting more qualitative or quantitative hypothesis testing, thereby contributing to the advancement of scientific knowledge.⁴³⁷ To this end, I concur with this point, given the potential to further dive into what PDoVs tell us about the current culture of value statements and rights mobilisation in healthcare. Information on the context of how human rights are violated can help non-government organizations leverage these findings to enhance their critiques and advocate for change.⁴³⁸

⁴³⁶ Richard. E. Boyatzis, *Transforming qualitative information: Thematic analysis and code development*. (Thousand Oaks, CA: Sage1998).

⁴³⁷ *Ibid*

⁴³⁸ Helen Watchirs, "Review of Methodologies Measuring Human Rights Implementation." (2002) 30:4 *The Journal of law, medicine & ethics*.

Reflexive thematic analysis was selected for this study because its fundamental characteristics align with the study's purpose and research questions. This method allowed for a focused and flexible exploration of human rights discourse, patient voice, and identity engagement, addressing my study's first objective: to understand how patient identity is currently conceptualised and discerning how advocacy and human rights fit into the discussion. In this research the primary themes that surfaced were derived from a combination of both inductive⁴³⁹ and deductive⁴⁴⁰ approaches. Moreover, my analysis scrutinized language with the PDoVS to comprehend and compare the data, but also to identify any omissions or “silences” within the data and how this related to larger contextual issues related to the emergence of *ECFAA*⁴⁴¹ legislation and citizen/patient participation in hospital affairs.

Undoubtedly, there are numerous qualitative methods for studying the discourses within documents such as those I present with the PDoVs. For instance, qualitative methods such as content analysis, interpret and quantify textual data, and allow researchers to sift through data to identify patterns, themes, or biases and turn these into quantifiable variables that can be further analyzed⁴⁴². Discourse analysis scrutinizes how knowledge is generated within various discourses, exploring the performances, linguistic styles, and rhetorical devices employed in specific narratives.⁴⁴³ These methods are not necessarily mutually exclusive however, and I opted to focus on thematic analysis for several reasons. While a method such as discourse

⁴³⁹ Inductive thematic analysis is an approach to coding and analyzing data that avoids imposing a pre-established coding scheme. Instead, it allows themes and patterns to emerge organically from the data, enabling a more open and exploratory examination.

⁴⁴⁰ Deductive thematic analysis, in contrast to inductive thematic analysis, involves applying a pre-existing theoretical framework or set of predetermined codes to the data.

⁴⁴¹ *Excellent Care for All Act*, *Supra* note 1.

⁴⁴² Kimberly Neuendorf, *The Content Analysis Guidebook*. Second Edition. (Thousand Oaks, California: SAGE Publications, 2017).

⁴⁴³ Dawn Snape, Liz Spencer, L. "The foundations of qualitative research." in J. Ritchie & J. Lewis eds., *Qualitative Research Practice*. (Sage Publications, 2003) at 12.

analysis could examine individual instances of language use and the nuances of (institutional) communication, it would potentially prioritize detailed exploration of language over a larger thematic overview relevant to the context of psychiatric care in Ontario more broadly. Given the objectives of my study and the need to grasp overarching patterns related to discourse and patient identity and advocacy, thematic analysis emerged as the more fitting approach. Thematic analysis provided a flexible and focused approach⁴⁴⁴ to identifying and understanding patterns or themes within the data, an opportunity to examine my own subjectivity and draw from my theoretical frameworks in order to offer a broader perspective on the data set, and its implications for epistemological considerations for service users within the context we find ourselves today. The aim has been to share a comprehensive picture and gain a nuanced understanding of how human rights, patient voice, and engagement are incorporated into the PDoVs through this method which involves a situated and interactive process that incorporates not only the data but also considers the researcher's positionality and current contextual elements inherent in the research as opposed to avoiding or ignoring their existence.

4.2 Limitations of research

My research is limited in the following ways: First, I downloaded the publicly posted PDoV statements from hospital websites, where (unless specified by each hospital) there is limited access to information about how PDoVs were initiated with stakeholders and what methods were used to develop the PDoVs. Second, my research is limited in that, I did not account for, or correlate other research variables such as demographic, population-based data, or for example,

⁴⁴⁴ Lorelli S. Nowell, Jill M. Norris, Deborah E. White, and Nancy J. Moules, "Thematic Analysis: Striving to Meet the Trustworthiness Criteria" (2017) 16:1 International Journal of Qualitative Method at 2.

the ethos of faith based hospitals on the creation of patient values statements.⁴⁴⁵ Thirdly, I did not correlate PDoV data with other elements of *ECFAA* legislation such as patient relations data and quality improvement plans.

From a methodological standpoint, this research is constrained by the absence of perspectives that encapsulate the lived experiences of PDoVs and the evolving or diminishing role of advocacy mechanisms, including the Office of the Patient Advocate. While the incorporation of interviews might have provided a more nuanced dataset, I deliberately opted against this approach due to limitations in resources and time, coupled with ethical concerns—particularly the risk of employing research methodologies that may inadvertently perpetuate exploitation. My extensive experience as a researcher, particularly in conducting focus groups and interviews (over many years at work) has deepened my understanding of the ethical complexities inherent in soliciting feedback from service users solely for research purposes.⁴⁴⁶ In previous projects designed to gather feedback for governmental initiatives, I encountered similar ethical dilemmas. To navigate these challenges, in the past, I employed collaborative and popular education methodologies, which are intended to democratize the research process and promote equitable opportunities for political engagement in research.⁴⁴⁷

⁴⁴⁵ This is of particular relevance given the emergence of Medical Assistance in Dying (MAiD), the role of Catholic hospitals refusing MAiD access at their sites, forced transfers and patient values. Please see: Eric Mathison “Canadian health care should put patients first by ending faith-based refusals” *The Globe and Mail* (July 7th 2023) online: <https://www.theglobeandmail.com/canada/british-columbia/article-canadian-health-care-should-put-patients-first-by-ending-faith-based/> [<https://perma.cc/3RGH-K7G4>]

⁴⁴⁶ For a similar discussion on the problem of ethics and community interviewing/engagement please see : Fern Brunger and Darlene Wall, "What Do They Really Mean by Partnerships?" *Questioning the Unquestionable Good in Ethics Guidelines Promoting Community Engagement in Indigenous Health Research*. (2016) Nov:26:13 *Qual Health Res.* at 1862.

⁴⁴⁷ As an example of an effort to engage in community capacity building and the processes of thinking and theorizing, please refer to the section "Methodically Crip" in Mel Y. Chen et al., “Crip Genealogies” (Duke University Press, 2023) at 19.

In my view, engaging service users in this context would have necessitated a more collaborative approach, integrating community and capacity-building initiatives to create a foundation for meaningful discussions on the complex impacts of legislation—particularly for a population likely unfamiliar with PDoVs or Patient Bills of Rights. In other sections of this research, such as the chapter addressing the divestment of the Psychiatric Patient Advocate Office, I have drawn upon evidence from news media and correspondence where available to substantiate the contextual dynamics of that period.

4.3 Reading the Data

While numerous authors⁴⁴⁸ have discussed thematic analysis (TA), this paper principally adopts Braun and Clarke's methodology for the identification, analysis, and interpretation of patterns of meaning ('themes') within the dataset.⁴⁴⁹ In 2018, Braun and Clarke went further to discuss the importance of reflexivity in TA stating that the researcher's role in knowledge production is at the centre of this method and that the researcher strives to be fully aware of the theoretical assumptions informing use of TA and that these theoretical assumptions are included consistently, and openly across the analysis and reporting phases.⁴⁵⁰ Reflexive thematic analysis is a method of examining research data with an objective of creating conceptual patterns ("themes") that address and respond to a research topic.⁴⁵¹ Typically, as service user and activist Rose notes, research projects often utilise thematic analysis and speak of themes as “emerging

⁴⁴⁸ For example please see: Jodi Aronson, “A pragmatic view of thematic analysis” (1994) Spring 2:1 The Qualitative Report; R. E Boyatzis. *Transforming qualitative information: Thematic analysis and code development*. (Thousand Oaks: Sage 1998); Kathryn Roulston, “Data Analysis and ‘Theorizing as Ideology’” (2001) 1:3 Qualitative research.

⁴⁴⁹ Victoria Clarke and Virginia Braun. “Thematic Analysis” (2017) 12:3 The journal of positive psychology.

⁴⁵⁰ Victoria Clarke and Virginia Braun, Nikki Hayfield ‘A starting point for your journey, not a map’: Nikki Hayfield in conversation with Virginia Braun and Victoria Clarke about thematic analysis, (2022) 19:2 Qualitative Research in Psychology at 424-445.

⁴⁵¹ Virginia Braun & Victoria Clarke “What Can ‘Thematic Analysis’ Offer Health and Wellbeing Researchers?” (2014) 9:1 International journal of qualitative studies on health and well-being.

from the data” but analytic work is always informed, openly or not, by the theoretical and epistemological underpinnings of the researcher(s).⁴⁵²

The justification for this method is the growing expansion of service user led research in mental health that uses thematic analysis as a method for clarifying the specifics of how groups (in this case, the state, and hospitals) conceptualize particular issues⁴⁵³. A second justification is that service users have written extensively about the challenges of addressing epistemic injustice given the continued reverence for positivist or empiricist scientific discourse rather than engendering and including alternative epistemologies.⁴⁵⁴ In the process of reflexive thematic analysis, I endeavoured to critically examine and utilize my perspective and subjectivity⁴⁵⁵ along with the insights of other service users/survivors who have extensively addressed the difficulties associated with mainstream research and participation regimes.⁴⁵⁶

As part of thematic analysis, I worked to both interrogate and harness my orientation and subjectivity. I was also aware of the pitfalls and inclination for “positivist creep”⁴⁵⁷ remembering the persistent emphasis and assumptions in mental health research inclined towards positivist

⁴⁵² Diana Rose, “Critical Qualitative Research on ‘madness’: Knowledge Making and Activism among Those Designated ‘mad.’” (2021) 6 Wellcome Open Research at 10.

⁴⁵³ Please see Helene Joffe, “Thematic Analysis.” in David Harper and Andrew R Thompson eds., *Qualitative Research Methods in Mental Health and Psychotherapy*. (Chichester, UK: John Wiley & Sons, 2011) where she discusses the expansion of mental health, service user led research that has significantly expanded in recent years and the growing body of research utilizing Thematic analysis.

⁴⁵⁴ Please see: Nev Jones and Robyn Brown, “The Absence of Psychiatric C/S/X Perspectives in Academic Discourse: Consequences and Implications.” (2012) 33:1 Disability studies quarterly and Diana Rose, 'Having a diagnosis is a qualification for the job'. (2003) 326:7402 British Medical Journal.

⁴⁵⁵ This research method required continual reflecting on my positionality, assumptions expectations, and choices throughout the research process.

⁴⁵⁶ Diana Rose and Peter Beresford, "PPI in psychiatry and the problem of knowledge" (2024) 24:1 BMC psychiatry at 52.

⁴⁵⁷ Virginia Braun, and Victoria Clarke *Thematic Analysis : a Practical Guide* (London: SAGE Publications, 2021) at 51.

values⁴⁵⁸ that are always assumed as 'balanced', 'detached' and 'scientific' while service users research continues to be viewed as weak⁴⁵⁹. To reiterate, Braun and Clarke define positivist creep as follows:

Positivist creep refers to the unknowing importation of values of quantitative positivist-empiricist research into qualitative research, such as valuing objectivity, control of 'bias', and the search for ultimate truth⁴⁶⁰

Being thoughtful of positivist creep and developing a diversity of codes was an important process of the research. Reflexive thematic analysis serves as a useful tool to illustrate or reveal the processes of social construction and how a particular representation develops.⁴⁶¹ In this case, I was looking at how patient voice is conceived and represented throughout the PDoVs. This method choice was ultimately driven by the nature of the examined data, primarily institutional documents, and the overall study design, which prioritizes meaning-making (inductive) as well as hypothesis testing (deductive) query.

4.4 Procedures

Initially, all 70 hospitals PDoVs were downloaded⁴⁶² from Schedule 1⁴⁶³ hospital websites and read through once in an effort to immerse myself in the data with the intention of determining inclusion criteria. After initial immersion into all 70 schedule 1 facilities PDoVs, I narrowed my

⁴⁵⁸ I am reminded of the coverage of the controversial resignation of Dr. Thomas Insel who in 2015 left the U.S.'s lead federal agency the National Institute of Mental Health (NIMH), stating, "I spent 13 years at NIMH really pushing on the neuroscience and genetics of mental disorders, and when I look back on that I realize that while I think I succeeded at getting lots of really cool papers published by cool scientists at fairly large costs—I think \$20 billion—I don't think we moved the needle in reducing suicide, reducing hospitalizations, improving recovery for the tens of millions of people who have mental illness."

⁴⁵⁹ Peter Beresford. "Developing the theoretical basis for service user/survivor-led research and equal involvement in research". 14:1 (2005) *Epidemiology and Psychiatric Sciences* at 6.

⁴⁶⁰ Virginia Braun, and Victoria Clarke. *Supra* note 453 at 448.

⁴⁶¹ Joffe, *Supra* note 449 at 211.

⁴⁶² PDoVs were initially downloaded in 2014 and 2015. Updated PDoVs were downloaded anew in 2021-2023.

⁴⁶³ Under *Ontario's Mental Health Act*, "Schedule 1" hospitals have the authority to admit individuals involuntarily, meaning without their consent. Such admissions require a physician's determination that the person meets specific criteria outlined in the *Ontario Mental Health Act*.

review to manage and focus specifically on nine Ontario facilities which receive services from the Ontario Psychiatric Patient Advocate office (PPAO) on their sites. If Ontario mental health patients contact the PPAO from a hospital outside of these nine core facilities, the PPAO will direct inquiries to that hospital's patient relations department or provide other referrals relevant to patient concerns.⁴⁶⁴ The excluded hospitals were typically hospitals with short-term service offerings, a limited number of mental health beds, and a predominant emphasis on medical conditions unrelated to mental health or addiction-related issues, such as cancer care, cardiac services, surgery, etc. This refined selection allowed for a more focused and relevant analysis, concentrating on facilities where the PPAO is accessible to patients. These nine facilities included: The Royal (Brockville), St. Joseph's Healthcare (Hamilton), Providence Care Hospital (Kingston), Parkwood Institute (London), Waypoint Centre for Mental Health (Penetanguishene), Southwest Centre for Forensic Mental Health Care (St. Thomas), St. Joseph's Health Care Group (Thunder Bay), The Centre for Addiction and Mental Health (Toronto) and Ontario Shores Centre for Mental Health Sciences (Whitby).

In collecting the data for this study, I undertook reflexive thematic analysis process using Braun and Clarke key elements and recent articulation of the process: 1) data familiarisation and writing familiarisation notes; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) refining, defining and naming themes.⁴⁶⁵

Step1. Data Familiarization

I focused on nine hospitals that provide comprehensive mental health treatment (and beds) and included access to PPAO services. These nine hospitals are facilities with a substantial number

⁴⁶⁴ Please see: "Advocacy services for patients" at PPAO online: website. www.ontario.ca/page/psychiatric-patient-advocate-office#contact [<https://perma.cc/BD29-HDPH>].

⁴⁶⁵ Braun and Clarke, *Supra* note 67 at 87.

of inpatient beds for mental health and/or forensic patients. They're the core hospital group designated to receive access to advocacy and rights advice from the PPAO. In other words, these nine hospitals include access to advocacy and rights advice infrastructure permitting me to explore and note how these PDoVs align or operate adjacently to the PPAO and/or, draw from service user knowledge⁴⁶⁶. Finally, I contacted each of the nine hospitals to confirm and request their PDoVs that outlined their core values as required by *ECFAA* legislation. I received email responses from all, confirming the authenticity of the documents under review.⁴⁶⁷

Of the nine hospitals chosen, some PDoVs were relatively short (a page or so) while others were paragraphs or pages longer. I examined how language, principles, and values were woven together to convey messages on behalf of patients, based on mandated consultation⁴⁶⁸ specifically, the study delved into how hospitals portray themselves as institutional voices or advocates through the messaging embedded in their PDoVs as of January 2022⁴⁶⁹. In addition, I looked at how PDoVs depict or make reference to the legal language and/or safeguards outlined in mental health laws. This inquiry aimed to address my second research question regarding how the themes in PDoVs point to human rights. Data collection also included familiarising myself with the accessibility of information on websites, learning about the scope of psychiatric services offered at each given site, and what, if any, patient group exist at each site (See Appendix A).

⁴⁶⁶ As I discussed in Chapter 2, the PPAO's goals, vision, and values have evolved from being a comprehensive complement of services to offering the minimum needs under the *Ontario Mental Health Act*.

⁴⁶⁷ In December 2023, I sent emails expressing my interest in locating the Patient Declaration of Values (PDoV), which outlines the hospital's core values as required by the *ECFAA* legislation. I requested guidance on where to find the specific section or document on your website containing the PDoV. Alternatively, if the document exists under a different title, I asked to be directed to the appropriate resource. Additionally, I inquired about any available information on the process for developing engagement for PDoVs.

⁴⁶⁸ *Excellent Care for All Act*, *Supra* note 1 at 7(1).

⁴⁶⁹ In 2015, I had downloaded Patient Declarations of Values (PDoVs), providing me with the capability to compare and contrast these documents over the last decade or so. This ability was instrumental in gaining insights into the evolving nature of PDoVs and understanding the changes that have transpired in this domain.

Close attention was paid to any descriptions about the nature and process for stakeholder engagement at the time and over the last decade of PDoV development. All PDoVs are available on the internet with varying levels of web user-friendliness.

Step 2. Systematic Data Coding

Phase I Manual Coding

Data extracted from each PDoV document underwent manual transfer into individualized Word documents, serving as the textual basis for analysis. In total, nine separate documents of varying lengths were printed for my analysis. The PDoV documents were printed and then carefully reviewed line by line, initiating the reflection process for organization of preliminary codes of meaning and patterns within the data text. To keep track of the initial codes, each document or text was subjected to coding, (via highlighting) with a corresponding comment box established in the margin with the applicable code/tag word. This method facilitated the aggregation of codes along with their respective supporting excerpts, thereby enabling comprehensive review of all excerpts organized by code.

Step 3. Generating initial themes from coded and collated data

The process of generating initial themes from coded data involved a wider level of analysis where I arranged the different codes into themes. Following Braun and Clarke's guidance,⁴⁷⁰ generating the initiation of preliminary themes, required deliberation about the shared meaning across the different sections of codes to determine what materialized in the PDoV data – deciphering the obvious from unobvious. It was important to determine whether a central and meaningful idea interconnected the data and codes at a deeper narrative level, beyond the explicit

⁴⁷⁰ Braun and Clarke, *Supra* note 67 at 453.

directives of the *ECFAA*⁴⁷¹. As an illustration, a preliminary theme evident throughout the dataset was the concept of "power." However, this theme, though prevalent as a potential aspect across various institutions, could encompass different interpretations within the data. It may involve the power derived from legislation, hierarchies, resources, or expertise.⁴⁷² Similarly, the theme of "rights" and the word "rights" is mentioned in each of the nine PDoVs, although not in a consistent manner. In light of this, even while "rights" serves as an overarching theme for the data set, its significance merited further development and review to explore which rights were overt and which were latent. Manual coding constituted the principal method employed in analysing the data set.

Phase 2 NVivo Coding

To ensure further thoroughness in my analysis, I subsequently also employed support from digital NVivo 14⁴⁷³ qualitative data analysis software for more inductive coding. All nine PDoV documents were uploaded to NVivo as separate files. Following this, I created code categories to organise the data files into codes. These codes were drawn from my initial results from my manual review of the dataset. Using NVivo also permitted organization of codes into a hierarchical structure, creating parent codes and sub codes to represent broader codes and sub-codes. For instance, see example in Table 1.

⁴⁷¹ *Excellent Care for All Act*, *Supra* note 1.

⁴⁷² Here, I am reflecting on Foucault's many discussions on discourse and power. Specifically his arguments that medical statements cannot come from anybody, their value, efficacy and existence as medical statements cannot be dissociated from the statutorily defined person who has the right to make them. See: Michel Foucault, *The archaeology of knowledge* (New York, NY: Routledge 1972) at 56.

⁴⁷³ NVivo is computer-assisted qualitative data analysis software that allows researchers to organize, analyze and visualize information such as text, and database tables. Version 14 of NVivo was employed to analyze all the qualitative data collected in the PDoVs in this study.

Following this process, all PDoV statements were also auto coded. The coding process proceeded until thematic saturation, identified recurring terms, phrases and concepts across the PDoV files and this generated a comprehensive total of 465 codes from the overview of the nine files generated and assigned to a codebook created using NVivo14. I then exported the lists of codes for review and compared them with results from my manual review.

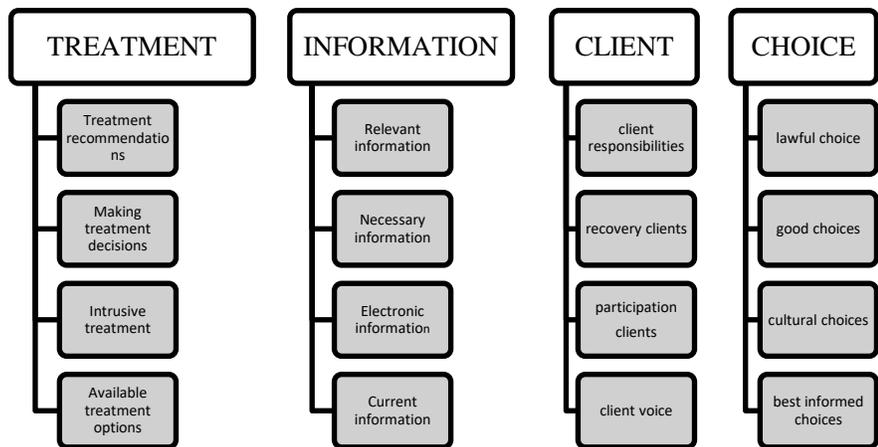


TABLE 1 *Hierarchy Treemap chart. This visualization uses one chart as an example to communicate parental codes and subcodes.*

After the preliminary examination of the codes generated by NVivo, which included word frequency analysis and tree mapping, I systematically identified and reviewed sentences and paragraphs containing conceptual ideas pertinent to my research questions. In this analysis, I scrutinized terms or expressions indicating an identifiable collective voice (patients/patienthood) or identity group, aiming to move beyond the generic implications of the term "patient" or "client" which lacks specificity. Additionally, I explored language in the PDOV codes and text signalling engagement with frameworks beyond medicine, such as the *Ontario Human Rights Code*⁴⁷⁴ or *Canadian Charter of Rights and Freedoms*⁴⁷⁵.

⁴⁷⁴ *Human Rights Code*, RSO 1990, c H.19.

⁴⁷⁵ *Canadian Charter of Rights and Freedom*, *Supra* note 216.

Step 4. Developing and reviewing themes

Themes from the PDoVS were re-examined by revisiting codes (terms and vocabulary) and drawing on the lens provided by Owens work on thematic interpretation which offers assistance in code interpretation by highlighting three criteria: recurrence, repetition, and forcefulness.⁴⁷⁶

Recurrence was observed when at least two parts of the dataset shared the same underlying meaning, even if expressed with different wording. For example, in many hospitals, the sentiment that patients should be valued and treated with respect was recurrent, though articulated in various ways. For instance at St Joseph's in Hamilton, "Being listened to and treated with respect and courtesy"⁴⁷⁷ is similarly recurrent in Providence Health Care hospital's PDoV when it states "I am an individual with my own feelings and needs, and that my dignity as a person must be respected by those who provide me care and services"⁴⁷⁸ or at the Parkwood Institute, "You know me by name; you seek to know who I am. You treat me with respect during the care I receive here and my privacy is important to you."⁴⁷⁹

The second criteria guiding theme development was the explicit repeated use of the same wording.⁴⁸⁰ For instance, to underscore a selection, terms like "respect" were employed 64 times, "right" recurred 243 times, "patient" appeared 145 times, "gender" occurred 5 times, "faith" 3 times, "race" 2 times, and "participate" registered 16 instances, with "disability" being mentioned

⁴⁷⁶ William Foster Owen, "Interpretive Themes in Relational Communication" (1984) 70:3 The Quarterly journal of speech at 275.

⁴⁷⁷ St. Joseph's Healthcare (Hamilton) "Patient Rights, Responsibilities & Declaration of Values" online: https://www.stjoes.ca/patients-visitors/patient-declaration-of-values/patients-right-and-responsibilities_march-2022.pdf [<https://perma.cc/D3YH-G43U>].

⁴⁷⁸ Providence Care Hospital (Kingston), online: "Patient, Client, & Resident Declaration of Values" online: Providence Care <<https://providencecare.ca/about-us/patient-client-resident-declaration-values/>> [<https://perma.cc/9G85-J6U2>].

⁴⁷⁹ Parkwood Institute (London), "Statement of Patient, Resident and Family Values" online: <https://www.sjhc.london.on.ca/patients-and-visitors/care-partnership/statement-of-patient-resident-family-values> [<https://perma.cc/X7X9-5JTF>]

⁴⁸⁰ Owen, *Supra note 472* at 275.

only once. The consistent use of some terms revealed how codes were repeated throughout the nine institutions under investigation. This repetitive use of language raises questions about the authenticity of the engagement process employed in formulating the statements. The consistent use of similar terminology across these facilities⁴⁸¹ prompts reflection on the underlying implications.

The third criteria forcefulness refers to vocal inflection, nonverbal vocal cues, or utterances or bold or italicized text in the data set⁴⁸². Forcefulness was not represented in PDoVs, given the nature of the texts – these were documents, not interviews and these statements were very general and repetitive in the vernacular. Having said this, The Brockville’s Royal hospital PDoV begins with an assertion characterising itself as a trailblazer in supporting the patient voice:

As a leader in specialized mental health, The Royal believes in including the client voice at the decision-making table. As a result, it is one of the few organizations in Canada that has embedded that philosophy into decisions on care, treatment and research since 2006⁴⁸³

A categorical and precise assertion, it obscures any events predating 2006. Providence Care in London employs a distinctive qualifier in its depiction of information access, asserting the patient's unequivocal right, "to information in order to foster good choices."⁴⁸⁴ “Good choices” implies that patients may make “bad choices” in spite of hospital information, a choice that does

⁴⁸¹ A substantial proportion of the 70 hospitals exhibited parallel lexical choices and expressions.

⁴⁸² Owen at *Supra* note at 472, 276.

⁴⁸³ The/ Royal Hospital (Brockville). “Client Declaration of Values” online: <https://www.theroyal.ca/patient-care-information/patients/client-statement-values> [https://perma.cc/G5KJ-6BTL]

⁴⁸⁴ Providence Care Hospital (Kingston), *Supra* note 474.

not align with a clinical directive. At CAMH, the *Bill of Patient Rights*⁴⁸⁵ under the right to be informed includes an unequivocal comment about information about treatments offered:

Every patient has the right to be informed of
c) the benefits, risks, side-effects, and costs (if any) of these options – including long-term and permanent risks”⁴⁸⁶

“Permanent risks” carries a weight and emphasis about the long term and everlasting impact of a treatment or intervention.

Step 5 Refining, defining and naming themes

This last phase in the research process required me to go over and improve dataset themes iteratively, to refine the content of each theme and how subthemes interact and connect to one another. Throughout this process, I made sure to explore other online hospital resources linked to PDoVS, such as details on patient councils or advisories at hospitals. The process was laborious and required breaks from the data collection in order to return to it with renewed attention while trying to maintain concentration on other relevant activities inside the nine institutions (such as patient advisory work or anti-racism work as well and attention to Indigenous items). In this way, I approached each PDoV as telling “its own story” and subsequently reflected and analysed codes from theoretical perspectives (i.e. Mad studies and standpoint based on my work in the mental health system itself).⁴⁸⁷

⁴⁸⁵ CAMH (Toronto). “Bill of Patient Rights” online: <https://www.camh.ca/en/your-care/your-rights/bill-of-patient-rights#:~:text=CAMH%20Bill%20of%20Patient%20Rights,Services%20that%20Comply%20with%20Standards> [<https://perma.cc/2F5W-TYJF>]

⁴⁸⁶ *Ibid* at Right #6 (c) Right To Be Informed.

⁴⁸⁷ Here I maintain that standpoint theory is essential for comprehending the epistemic consequences of marginalization of service users, whether through PDoVs or other documents. I make this point on the assertion that we must consider both the importance of situated knowledge and the conditions conducive to question and change perspectives particularly in this context of the emergent regimes of engagement and civic participation. Please see: Sandra Harding, *Whose Science? Whose Knowledge? Thinking from Women's Lives*, (Ithaca, NY: Cornell University Press 1991); Heidi E Grasswick “Individuals-in-Communities: The Search for a Feminist Model of Epistemic Subjects” (2004) 19:3 *Hypatia* 85–120.

In this process I used existing theory⁴⁸⁸ as the interpretive lens to make sense of the data. I was interested in learning how the patterns in PDoVs relate to notions of mental health and conceptual theories of patient involvement⁴⁸⁹. Instead of merely summarizing PDoVs, I was interested in how these hospital PDoVs and themes relate to Mad Studies and challenges in the healthcare system pertaining to public management regimes impacting people with psychiatric disabilities⁴⁹⁰, market competition⁴⁹¹ (the quantifiable self)⁴⁹² as well as the ability of technology to turn those who receive healthcare into passive consumers of services⁴⁹³. As such, this research study has been guided by a desire to explore the research questions and an ongoing, reflection on the methodology itself in order to convey the story value statements reveal, as opposed to adhering to clinical paradigms that are not initiated by the patients themselves.

My final analysis included a review using a deductive approach based on principles rooted in the experiences of service users found in the literature and my research questions. This entailed the exploration of topics related to informed consent, access to health-related information, treatment specifics, principles advocating for patient autonomy and advocacy, reflections on equality and non-discrimination, discussions concerning psychiatric authority, encouragement for service user

⁴⁸⁸ Please see: Kathryn Church. "It's complicated': blending disability and mad studies in the corporatising university." in Helen Spandler Jill Anderson, and Bob Sapey *Madness, distress and the politics of disablement*. (Bristol: Policy Press, 2015) at 261-270 and Sarah Carr, "Institutional ceremonies?: The (im) possibilities of transformative co-production in mental health." in Peter Beresford and Jasna Russo eds. *The Routledge International Handbook of Mad Studies*. (Routledge, 2021) at 142.

⁴⁸⁹ Rose, *Supra* note 402 at Part II.

⁴⁹⁰ David Mitchell and Sharon L Snyder, *The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment*. (Ann Arbor: University of Michigan Press, 2015).

⁴⁹¹ I began this study by commenting on the degree to which all hospitals publicise their slogan emphasising attributes and statements of promise and care. page 3 Hospitals often use slogans and branding to differentiate themselves in a competitive healthcare market. Adopting similar strategies is a way to emulate their success or align with perceived industry standards.

⁴⁹² Deborah Lupton, "Quantifying the Body: Monitoring and Measuring Health in the Age of mHealth Technologies." (2013) 23:4 *Critical public health*.

⁴⁹³ Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. (Princeton: Princeton University Press, 2009).

involvement in mental health care decisions, references to advocacy offices and their complaint procedures, and explicit discourse on laws associated with psychiatric facilities. Upon revisiting the collected themes, I generated overview points for each of the nine hospitals. In essence, I systematically reworked this data to distill essential conceptual ideas at each of the nine hospitals. I also identified common themes and consolidated them into more concise categories to address my research questions. See Table 2

TABLE 2 Summary of Major Themes

Main Theme	Sub Themes	Summary Of Theme
Responsibilization and Presumptive Contracts	<p>Highlighting the rights and responsibilities of patients & staff</p> <ul style="list-style-type: none"> • duty to respond, act, or act • providing correct and complete information about medical history • treating the healthcare team with courtesy and respect. <p>Feedback and Improvement:</p> <ul style="list-style-type: none"> • Encouraging patients to provide feedback about their care and share any concerns. <p>Collaboration</p> <ul style="list-style-type: none"> • Enhance care and services. • Patient Involvement and participation • Working collaboratively to determine the next steps in the patient's care. 	<p>This theme unpacks the ways in which the healthcare system delegates responsibility on to patient. It delves into the responsibilities associated with being a patient, as well as the encouraged role in engaging with healthcare staff. The significance of this theme in my research lies in its emphasis on the portrayal of patients not as passive recipients but as active participants in their care. As such, I analyse how this activity interfaces with historical epistemic challenges for service users and the inherent tensions surrounding legal support.</p>
Respectability	<p>Culture of Respect</p> <ul style="list-style-type: none"> • Treated with courtesy, respect, and dignity. <p>Working in good faith</p> <ul style="list-style-type: none"> • Healthcare team members treated with courtesy and respect. <p>Dignity</p> <ul style="list-style-type: none"> • Being treated in a manner that respects dignity and privacy. <p>The environment</p> <ul style="list-style-type: none"> • Care, Restrictive, sleeping, therapeutic 	<p>This thematic examination scrutinizes the operationalization of respectability within PDoVs. It specifically investigates the manner in which dignity and respect are extended to individuals within institutional contexts, evaluating the potential implications for bias or disparate allocations of respect and dignity. Additionally, this theme explores the dynamics of power and its correlation with the politics of respect.</p>
Patient Subjectivity	<p>Individuality and Autonomy:</p> <ul style="list-style-type: none"> • Patient choice / informed decision making Individualized written plan of care <p>Cultural, ethnic, spiritual, linguistic, and regional differences.</p> <ul style="list-style-type: none"> • Recovery and Support: • Recovery goals. 	<p>This theme elucidates the portrayal and construction of patients within PDoVs and examines the interrelation between this representation and the domains of mental health, hospital contexts, and legal frameworks. The focus is directed towards delineating the roles attributed to patients within institutional settings as</p>

		articulated in these textual narratives conveying values.
Law as Elusive	<p>Information:</p> <ul style="list-style-type: none"> • Being informed on personal health information & accurate medical information. • Accurate information, electronic information <p>Advocacy</p> <ul style="list-style-type: none"> • Decision-Making • Refusing treatments clinical consequences • Complaint without retribution. <p>Safety and Security:</p> <ul style="list-style-type: none"> • Right not to have freedom and less restrictive space • Privacy <p>Cultural and Spiritual Considerations</p>	<p>This theme is centred on the pivotal concept of law, and relevant Acts, including the Mental Health Act, Health Care Consent Act, Privacy legislation, The Human Rights Code, and the Charter of Rights and Freedoms. It integrates these into (PDoVs) without overtly citing distinct legislation or legal doctrines. The significance of this theme within the broader scope of my research resides in its illumination of the dual nature of law, both transparent and opaque, as discerned within PDoV statements and/or engagement initiatives.</p>

The initial set of themes were subsequently refined to four themes in correspondence with the specific parameters of my research and the principles of the theoretical framework. The themes derived from the data show a schism between the discourses of the text, the assumptions that patient engagement contributed to the expression of this terminological landscape.

Chapter 5 FINDINGS

*As a client, I have the responsibility to be a leader in my care*⁴⁹⁴

In this chapter I expand on the primary objective of the research undertaken, which is the identification of discourse(s) marshalled within the PDoVs. As discussed in chapter 4, the outcomes of this study were documented through an initial review using thematic analysis⁴⁹⁵ as well as utilizing NVivo coding. This analytical process was undertaken to identify and discern prevalent themes within the PDoV dataset and the documentation is substantiated through direct examples extracted from the dataset, serving as empirical evidence for illustrating the identified themes.

In this chapter I discuss four overarching themes from the PDoVs, exploring how they shape the hospital language within the *ECFAA*⁴⁹⁶ and how they influence our contemporary understanding of patient representation and engagement in healthcare. These themes are detailed in Tables 3 to 6, and a concise overview of each hospital's specifications is available in Appendix A. These four dataset themes show the following: an imperative for responsiveness as well as the establishment of a responsabilizing environment, wherein patient participation is subtly intertwined with the delegation of patient responsibility. Additionally, the data delves into discussions surrounding "respect" in hospitals, promoting a culture of respectability. The third theme expounds on the language and representation or subjectivity ascribed to patients within the PDoVs. Lastly, my fourth theme scrutinizes the transparent and hidden legal frameworks in

⁴⁹⁴ St. Joseph's Health Care Group (Thunder Bay) online: <https://sjcg.net/documents/brochures/Client-Rights-Responsibilities-Brochure.pdf> [<https://perma.cc/7KYR-QNS9>]

⁴⁹⁵ Braun and Clarke, *Supra* note 67.

⁴⁹⁶ *Excellent Care for All Act*, *Supra* note 1.

PDoVs, revealing associations with legislative *Acts* and characterizing the legal dimension as somewhat visible but also elusive.

5.1 Theme 1. Responsibilization and Presumptive Contracts

The PDoV data for theme one combined in three parts, elucidates recurring themes of responsabilization, responsiveness and responsibility, wherein hospitals delineate their duty to respond, act, or commit to actions in the optimal interest of patients (Table 3a). On the flip side, specific hospital value statements highlight the mutual dimension of patient responsibility (Table 3b), accentuating the patient's obligation not just to the hospital but also to fellow patients and the environment. Moreover, there are prompts suggesting that patients function as “participating partners” (Table 3c) in a presumed form of deliberative democratic processes aimed at enhancing hospital services. These responsibilities encapsulate a dual commitment—committing to undertake specific actions and fostering a sense of trustworthiness within the hospital interpersonal relationships that are *responsive* and *responsible*. Thus in this context the data reveals that within the expectations of patient responsabilization and participation lie other social contractual negotiations by virtue of the reciprocal relationships articulated through relationships of hospital care obligations and as such, subsequent collectivities and interdependencies.⁴⁹⁷

The data in Table 3a highlights the responses/responsibilities of three hospitals to their patients as opposed to those in Table 3b which illustrates examples from four hospitals

⁴⁹⁷ Nikolas Rose has discussed that through new modes of responsabilization, the 'social' might be shifting to 'the community' as a new area for managing individual and collective life, a new space where small-scale moral relations among people are thought about and managed in Nikolas. Rose, “The death of the social? Re-figuring the territory of government” (1996) 25:3 *Economy and Society* at 331.

articulating the responsibilities of patients themselves. For instance, CAMH’s PDoV is endorsed by their Board of Trustees and this is stated at the beginning of the document. It emphasizes the expectation that all individuals associated with CAMH, including volunteers and students, uphold and promote awareness of the CAMH Bill of Patient Rights⁴⁹⁸. The enumerated rights include the patient's entitlement to comprehensive information about services, provider qualifications, treatment recommendations, access to additional information, and the right to involve substitute decision-makers in the decision-making process if deemed incapable. For Waypoint, their PDoV emphasizes a commitment to respond and collaborate with patients so they understand and support advised behavioural changes, allowing them to view their clinical records with explanations from clinicians⁴⁹⁹. Parkwood hospital outlines their obligation as leaders to address issues or complaints, emphasizing the importance of gathering information and taking necessary actions. Lastly, the encouragement of patient input, even beyond their care team, reflects a commitment to inclusivity and collaboration within the healthcare setting.

⁴⁹⁸ CAMH (Toronto), “Bill of Patient Rights” *Supra* note 481.

⁴⁹⁹ Waypoint Centre for Mental Health Care (Penetanguishene), “Declaration of Recovery Values” *Supra* note 176.

TABLE 3a Duty to Respond

Sites	Representative Data
Centre for Addiction and Mental Health (CAMH) (Toronto)	<ul style="list-style-type: none"> • The Board of Trustees of the CAMH endorses the Bill of Patient Rights and, , expects that CAMH and every one working at CAMH – will uphold the Bill of Patient Rights ...and will interpret the Bill of Patient Rights as broadly and generously as is consistent with their responsibilities to patients.⁵⁰⁰ • Every patient has the right to meaningful answers to questions about services⁵⁰¹ • If found incapable, has the right to expect that their SDM will make decisions on their behalf in accordance with their legal obligations (including taking into account any prior wishes expressed by the patient while capable that apply in the circumstances)⁵⁰²
Waypoint Centre for Mental Health (Penetanguishene)	<ul style="list-style-type: none"> • That we will work with you to understand your behaviour and support you to make changes. We will explain our responses to your behaviour • That you can view your clinical record if you wish. A clinician can be with you when you view it so you can have questions answered.⁵⁰³
Parkwood Institute (London)	<ul style="list-style-type: none"> • “Once an issue or complaint is brought to a leader’s attention, he/she has an obligation to follow up, to meet with all affected parties to gather information and understand the facts involved, and to take the necessary action”⁵⁰⁴ • Patient input is encouraged by the Coordinator or Director of your unit, even if it's unrelated to your care team as this “input is also welcomed by the Coordinator or Director responsible for your unit.”⁵⁰⁵

In Table 3b, the data underscores the fundamental principles of patient responsibilities in healthcare institutions. Parkwood Institute emphasizes the obligation of patients, family members, and visitors to treat others with respect, actively engage in their care, and safeguard personal property and financial obligations⁵⁰⁶. St. Joseph’s Health Care Group outlines client responsibilities, urging individuals to exhibit respect, maintain confidentiality,

⁵⁰⁰ CAMH, “Bill of Patient Rights” Supra note 481 at p2.

⁵⁰¹ *Ibid*, at right #6.3

⁵⁰² *Ibid*

⁵⁰³ Waypoint Centre for Mental Health Care (Penetanguishene), “Declaration of Recovery Values” Supra note 176.

⁵⁰⁴ Parkwood Institute (London). Statement of Patient, Resident and Family Values online: <https://www.sjhc.london.on.ca/patients-and-visitors/care-partnership/statement-of-patient-resident-family-values>[<https://perma.cc/X7X9-5JTF>] and “Mental Health Care Patient Bill of Rights” [<https://perma.cc/R4QU-VJL5>].

⁵⁰⁵ *Ibid*

⁵⁰⁶ *Ibid* at 21.

lead in their care decisions, and support safety practices⁵⁰⁷. St. Joseph’s Healthcare in Hamilton extends patient and family responsibilities to include providing accurate medical information, treating healthcare teams with courtesy, respecting hospital property, and actively participating in care planning⁵⁰⁸. Ontario Shores Centre for Mental Health Sciences in Whitby emphasizes patient participation in their care, effective communication with healthcare teams, the importance of treating others with dignity, and the responsibility to maintain personal and others' safety⁵⁰⁹. Overall, the data highlights a consistent theme of promoting engaged, and responsible patient behaviour across these four of the nine healthcare institutions.

TABLE 3b Patient Responsibility

Sites	Representative Data
Parkwood Institute (London)	<p>How Patients, Family Members, and Visitors Treat Staff</p> <ol style="list-style-type: none"> 1. Patients, family members, and visitors have the responsibility to: 2. Treat others with respect 3. Actively partner in their care 4. Protect personal property and financial obligations
St. Joseph’s Health Care Group (Thunder Bay)	<p>Client Responsibilities By partnering with others on my care team to make decisions about my care, and by treating others with respect and dignity, I am able to experience the best care possible. As a client of St. Joseph’s Care Group, I have responsibilities to other clients, family members, staff, physicians, volunteers and visitors.</p> <p>As a Client, I Have the Responsibility to:</p> <p>Show Respect</p> <ul style="list-style-type: none"> • Treat others with courtesy and consideration at all times <p>Maintain Confidentiality</p> <ul style="list-style-type: none"> • Respect the privacy of others by refraining from sharing any written, verbal or electronic information of others without

⁵⁰⁷ St. Joseph’s Health Care Group (Thunderbay), “Client Rights and Responsibilities” online: <https://sjcg.net/documents/brochures/Client-Rights-Responsibilities-Brochure.pdf> [<https://perma.cc/7KYR-QNS9>]

⁵⁰⁸ St. Joseph’s Healthcare (Hamilton), Supra note 473
 “Patient and Family Declaration of Values” Online: https://www.stjoes.ca/patients-visitors/patient-declaration-of-values/a15052_declarationofpatientvalues-final-july-2023.pdf [<https://perma.cc/FN8V-ASGR>]

⁵⁰⁹ Ontario Shores Centre for Mental Health Sciences (Whitby), “Patient Rights and Responsibilities” online: <https://www.ontarioshores.ca/patient-rights-and-responsibilities> [<https://perma.cc/357J-MB8U>]

	<p>their consent</p> <p>Be A Leader In My Care</p> <ul style="list-style-type: none"> • Participate in making decisions about my care • Ask questions when I don't understand information provided to me • Provide relevant information to members of my care team to help them in making decisions about my care • Respect my care providers and their time with me • Report any concern to staff or a manager <p>Support Safety</p> <ul style="list-style-type: none"> • Recognize and follow safety practices • Treat supplies, equipment and furnishings with respect • Report to staff anything I believe needs attention with regard to safety or security⁵¹⁰
St. Joseph's Healthcare (Hamilton)	<p>As a patient or family member, it is your Responsibility, when able to:</p> <ul style="list-style-type: none"> • Provide correct and complete information about your current and previous medical history. • Treat your healthcare team with courtesy and respect. • Be mindful of the healthcare team's obligations to other patients. • Respect hospital property, policies and rules. • Be considerate of the rights and property of others. • Ask questions about information and instructions that are not understood. • Notify the appropriate departments if unable to keep your appointments. • Participate in planning your care at the level that you choose.
Ontario Shores Centre for Mental Health Sciences (Whitby)	<p>Patient Responsibilities</p> <ul style="list-style-type: none"> • Participate in your care • Communicate with your health care team • Treat others with dignity and respect • Keep yourself and others safe

In Table 3c the data from all nine hospitals underscores an emphasis on patient participation in various aspects of their healthcare encompassing efforts to reform prevailing practices and/or actively engage in research. As such, the data illustrates a transformative shift portraying patients not merely as passive clinical subjects but rather as integral civic actors⁵¹¹ in the psychiatric

⁵¹⁰ St. Joseph's Health Care Group (Thunderbay), *Supra* note 502.

⁵¹¹ For more on how patients are increasingly recognized as active contributors in healthcare rather than passive recipients please see: Sonya Erikainen, Martyn Pickersgill M, Sarah Cunningham-Burley, Sarah Chan. "Patienthood And Participation in the digital era" (2019) 5 Digital Health.

healthcare landscape. At CAMH the data demonstrates that patients are to be informed about release from restraint, the right to fair access to treatments, and their right to provide feedback for treatment improvement on their very experience of restraint. The Royal and Ontario Shores underscore patient participation in decision-making and informed choices. Parkwood Institute advocates for patients as partners in care, ensuring their voices are heard. Providence Care Hospital’s PDoV emphasizes explicitly the right to form friendships and participate in the hospital community. Southwest Centre for Forensic Mental Health Care asserts patients will participate in their care. St. Joseph’s Health Care Group recognizes patients as experts in their needs and should therefore participate in their care. St. Joseph’s Healthcare prioritizes client engagement and informed decision-making. Waypoint Centre for Mental Health supports therapeutic activities for recovery and respects patients' decisions to participate in research.

TABLE 3c Participation

Sites	Representative Data
Centre for Addiction and Mental Health (CAMH) (Toronto)	<ul style="list-style-type: none"> • Patients will be informed how to be released from restraint, will be offered a supportive and respectful debriefing, and will be involved in reviewing and revising their care plan if needed; • has the right to fair and equal access to and choice from the range of CAMH treatments and services available (both clinical and non-clinical), and to culturally-based healing modalities (e.g., smudging, etc.), and to reasonable accommodations that are required to support their participation; • has the right to provide feedback about their care and to participate in opportunities aimed at improving the quality of services. • has the right to clear, honest, direct and supportive communication with service providers that recognizes and seeks to mitigate the power imbalance and its impact (e.g., clear language, transparency, how to participate to reach own ends, etc.); • has the right to give informed consent for participation in research or as otherwise as determined by the Research Ethics Board; • who consents to participate in research has the right to be informed of research goals and results;
The Royal (Brockville):	Core Value Three: Engagement and Participation Clients are active participants in their safety, health care and health care decision making.

	<p>Core Value Four: Informed Decision Making</p> <p>Clients have access to reliable and current information about their health care options, in order to support informed decision making and active participation in care.</p>
Ontario Shores Centre for Mental Health Sciences (Whitby)	<p>Patient Responsibilities</p> <p>Participate in your care.</p>
Parkwood Institute (London)	<p>Participation – I am a partner in my care.</p> <ul style="list-style-type: none"> • My voice is important to you. Keep me, with the support of others whom I choose to be part of my circle of care, fully informed of my health condition so I can participate • has the right to participate in creating an individualized, written plan of care and service and receive a copy of it; • has the right to be involved in their discharge/transfer planning and to be notified in a timely way of the discharge/transfer date
Providence Care Hospital (Kingston)	<p>Right to form friendships and relationships and to participate in the life of the long-term care home, hospital or community service program.</p>
Southwest Centre for Forensic Mental Health Care (St. Thomas)	<p>Actively partner in their care</p>
St. Joseph's Health Care Group (Thunder Bay)	<ul style="list-style-type: none"> • Be recognized as an expert in my needs and have the opportunity to participate in making decisions about my care • Have engagement activities (including surveys, focus groups, research studies and other) explained to me before being invited to voluntarily participate • Provide my consent to participate and withdraw my consent and participation at any time during any engagement activity • Be A Leader In My Care • Participate in making decisions about my care
St. Joseph's Healthcare (Hamilton)	<ul style="list-style-type: none"> • Participate as part of the healthcare team in developing your plan of care. • Having a voice of their own or through whomever they choose. • Participating in care at the level chosen by the patient.
Waypoint Centre for Mental Health (Penetanguishene)	<p>A variety of therapeutic activities to support your recovery including recreation, leisure opportunities, education, and employment support, as resources and availability permit.</p> <ul style="list-style-type: none"> • That if you have any feedback about your care, either positive or negative, you can speak to the involved person directly or to the manager of the program, or follow the process outline in the Waypoint Complaints Reporting Policy.

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- To have one's decision to **participate** in research or to decline to participate in research respected, and to not be pressured to participate if you are not comfortable doing so.

As a central theme, the process of responsabilization, manifested through institutional responses, patient responsibilities, and civic dimensions of patient participation, encompasses the performance of specific actions and the cultivation of trustworthiness within interpersonal and social connections across the nine hospitals. While empowering patients to be active participants in their care is a positive aspect, there's a need for further critical examination which I discuss in chapter 6. The extent to which these opportunities are emphasized for patients should be scrutinized to ensure that it does not lead to undue burden, especially for those already dealing with mental health distress as this can become harmful⁵¹².

5.2 Theme 2. Respectability

The nexus of respectability and responsibility are intertwined important themes that delineate how PDoVs map out medical discourse concerning appropriate healthcare practices and directives that encourage practices be respectable versus disrespectful, or abusive to patients and staff. These extracts become insightful when considered in the broader context, as psychiatric

⁵¹² Dawn P Richards. et al. "Reflections on patient engagement by patient partners: how it can go wrong." (2023) 9:1 Research Involvement and Engagement at 8.

sites have historically been sites that contain degeneracy⁵¹³ and protect and promote the cultivation of morality and respectability.⁵¹⁴

The findings from various mental health institutions, including CAMH, Royal, Ontario Shores Centre for Mental Health Sciences, Parkwood Institute, Providence Care Hospital, Southwest Centre for Forensic Mental Health Care, St. Joseph’s Health Care Group, St. Joseph’s Healthcare, and Waypoint Centre for Mental Health, collectively underscore a shared commitment to upholding the principles of respect in patient care. Patients, families, and staff collaborate to develop living documents such as the Bills of Patient Rights, aiming to foster organizational cultures characterized by mutual respect. For example the Parkwood Institute PDoV states that confidence is earned through respect.⁵¹⁵ In this theme, there is an emphasis on courtesy, compassion, and involvement in decision-making processes that points to a dedication to providing personalized and *respectful* mental health care services to individuals accessing these services.

TABLE 4 Respectability

Sites	Representative Data
Centre for Addiction and Mental Health (CAMH) (Toronto)	<ul style="list-style-type: none"> <li data-bbox="532 1310 1443 1453">The patients, families and staff of CAMH who have worked together to develop the Bill of Patient Rights want it to be a living document that will grow and change as it helps to foster an organizational culture of mutual respect.

⁵¹³ Please see: Mary Louise Fellows and Sherene Razack, “The Race to Innocence: Confronting Hierarchical Relations among Women” (1998) 335:1 Journal Gender Race & Justice where they discuss the concepts of respectability and degeneracy as integral components of ideological discourse, symbolizing power dynamics that served the middle class and provided a justification for asserting dominance over those deemed degenerate within society.

⁵¹⁴ James E. Moran's book offers a thorough overview of the evolution of asylums as a response to madness in Quebec and Ontario and his argument emphasizes that asylums stemmed from complex relationships among various stakeholders such state administrators, asylum doctors, local magistrates, and religious authorities and including the work the leveraging of moral therapy and social control. James E Moran. *Committed to the State Asylum Insanity and Society in Nineteenth-Century Quebec and Ontario*. (Montréal [Que: McGill-Queen’s University Press 2000).

⁵¹⁵ Parkwood Institute (London), *Supra* note: 499

	<ul style="list-style-type: none"> • is a person first, with the right to this recognition and to respect before the law; • has the right to be treated without discrimination, and to have their culture, spirituality, atheism, or identity respected; • will be offered a supportive and respectful debriefing, • has the right to have their privacy respected in the company of other people; • has the right to a sexually safe environment that promotes privacy, is respectful of intimacy needs • has the right to be treated with fairness, in a manner that is respectful of patient-identified needs and preferences; • Rights in Respect of Research or Teaching
The Royal (Brockville)	Core Value Two: Dignity and Respect Clients and families are treated with dignity, compassion and respect.
Ontario Shores Centre for Mental Health Sciences (Whitby)	Ontario Shores values Respect for all individuals Right to be treated with respect treat others with dignity and respect
Parkwood Institute (London)	<ul style="list-style-type: none"> • Earning my complete confidence starts with respect, excellence and compassion. • You treat me with respect during the care I receive here and my privacy is important to you.
Providence Care Hospital (Kingston)	<ul style="list-style-type: none"> • Your voice is important and respected. • As a patient, client or resident of Providence Care, I value respect. To me, this means I have the right to be treated with respect by those who are providing care • Right to be treated with courtesy and respect and to be free from mental and physical abuse. • Right to be treated in a manner that recognizes my individuality and that respects my dignity, and cultural, ethnic, spiritual, linguistic and regional differences. • my dignity as a person must be respected by those who provide me care and services. • Right to be treated in a manner that respects my dignity and privacy and that promotes my autonomy. • Right to have my lifestyle and my choices respected.
Southwest Centre for Forensic Mental Health Care (St. Thomas)	<ul style="list-style-type: none"> • The patients, families and staff who have worked together to develop the Patient’s Bill of Rights wish it to be a living document which will grow, evolve and continue to create an organizational culture of mutual respect and trust. • Every patient has the right to be treated with respect • Every patient has rights in respect of research or teaching Respect <ul style="list-style-type: none"> • for my privacy • that I am part of my own care team along with the family support

	<p>I see fit</p> <ul style="list-style-type: none"> • for my time – waiting for appointments; waiting for call bells to be answered; not rushing my time with the doctor and team; receiving results in a timely way
St. Joseph’s Health Care Group (Thunder Bay)	<ul style="list-style-type: none"> • As a client of St. Joseph’s Care Group, my unique wants and needs will be acknowledged. Family and/or others who I choose to be included in my care are important partners who help lead decisions about my care and are treated with dignity and respect at all times. • By partnering with others on my care team to make decisions about my care, and by treating others with respect and dignity, I am able to experience the best care possible <p>Show Respect</p> <ul style="list-style-type: none"> • Treat others with courtesy and consideration at all times • Respect the confidentiality of others • Treat supplies, equipment and furnishings with care and respect
St. Joseph’s Healthcare (Hamilton)	<p>Respect and Dignity</p> <ul style="list-style-type: none"> • Respect patient’s individual identity, beliefs, history, culture and ability • Respect and support patients’ right to make informed choices • Treat everyone with respect, • Ensure patient personal health information remains private, respected and protected.
Waypoint Centre for Mental Health (Penetanguishene)	<ul style="list-style-type: none"> • We will treat people with kindness, dignity and respect. • To be treated fairly and with respect, regardless of your personal identity and circumstances, according to the vision, mission and values of Waypoint, the Ontario Human Rights Code and the Canadian Charter of Rights and Freedoms. • We will respect your right to privacy, including sexual activity between consenting adults. • treat people with kindness, dignity and respect. • That you will be heard fairly and with respect, according to the Waypoint vision, mission and values and the Employee Code of Conduct. • To have one’s decision to participate in research or to decline to participate in research respected

In the subsequent chapter, I critically explore the limitations inherent in the discourses of respect within hospital environments. Furthermore, I scrutinize the potential risks associated with a conceptual shift that reorients the notion of “respect” towards a politic of deference to authority

5.3 Theme 3: Patient Subjectivity

Patient subjectivity, as I use the term, involves how patients are shaped as subjects through medicine and the law, particularly through PDoVs; this shaping process expresses narratives and discourses related to psychiatric patients, patienthood, and patient identity. In Table 5 patients are conceived primarily through an autonomous model which recognises the individuality and distinct needs of patients. Identity emerges as a significant theme in Table 5, emphasizing discourses such as “client voice”, the value of “the individual” as well as acknowledgment and respect for individual identities, beliefs, and cultural backgrounds. The concept of patient choice is emphasized as a value stating patients should or will have a say in their treatment and care. The emphasis on choice is evident, emphasizing patients' rights to fair access, and collaboration in treatment plans. Additionally, "informed decision-making" was integral to the PDoV text, highlighting the importance of patients having comprehensive information about their treatment in hospitals to make informed choices. The PDoV from Parkwood for example, emphasizes, “my voice is important to you.”⁵¹⁶ The findings show that institutions like The Royal, Parkwood Institute, St. Joseph’s Health Care Group, and Waypoint stress the importance of incorporating the client's voice, ensuring informed decision-making, and supporting choices that align with individual preferences. Overall, the data findings collectively portray what appears to be a commitment to promoting patient autonomy, respect for diverse identities, and the facilitation of informed choices in mental health care as well as an understanding that in the healthcare setting, every patient brings their own set of beliefs and expectations influenced by their individual identities, culture, religious beliefs, sex, age, etc.

⁵¹⁶*Ibid*

TABLE 5 Patient Subjectivity

Sites:	Representative Data
The Royal (Brockville)	<ul style="list-style-type: none"> • As a leader in specialized mental health, The Royal believes in including the client voice at the decision-making table. • Core Value Seven: Recovery Clients receive care in a therapeutic environment that supports hope and recovery
Parkwood Institute (London)	<p>My voice is important to you.</p> <ul style="list-style-type: none"> • The Patient Council is a group of current and former patients of St. Joseph’s that volunteer their time to serve as a voice for the ongoing improvement of the quality of life and care of patients. • Has the right to co-operation and collaboration among providers to ensure quality and continuity of patient centred care (including integration with other healing practices), in support of wellness and recovery; • the right to be treated in a respectful manner, regardless of their race, culture, colour, religion, sex, age, mental or physical disability, class/economic position, sexual orientation, gender identity, • manner that respects the dignity, independence and self-determination of the individual; • participate in creating an individualized, written plan of care and service and receive a copy of it; • I can participate in the best-informed choices about my care. Understand the choices I make today, may be different than my choices tomorrow. • has the right to contact with clergy or other spiritual advisors of their choice, and to exercise religious and spiritual observances, rituals, customs and dress • has the right to a choice of services, and will not be denied other options if the patient does not choose one treatment or sight to sufficient, nutritious and palatable food, in accordance with medical and religious requirements, and with consideration of personal and cultural choices; • has the right to be involved in their discharge/transfer planning and to be notified in a timely way of the discharge/transfer date (This may include, upon the request of the patient, notification of a person of their choice); • has the right to have access to information about various support options available in the community, including peer support and

	<p>self-help organizations.</p> <ul style="list-style-type: none"> • has the right to visits from support persons of their choice, and assistance in contacting them; • has the right to access confidential support when needed: counselling, rights advice, advocacy, legal counsel, other supports of their choice • Every patient has the right to have a person of their choice to support them through the complaint process
St. Joseph's Health Care Group (Thunder Bay)	<p>Share my voice and help make improvements</p> <ul style="list-style-type: none"> • Be provided information about my health, treatment options and consent to treatment in a way that I understand and at my request
St. Joseph's Healthcare (Hamilton)	<ul style="list-style-type: none"> • Respect patient's individual identity, beliefs, history, culture and ability.
Centre for Addiction and Mental Health (CAMH) (Toronto)	<ul style="list-style-type: none"> • to have their culture, spirituality, atheism, or identity respected; • has the right to self-identify and be recognized for their gender, gender identity, gender expression and sexual orientation, including but not limited to name, pronouns, and expression. • assistance in securing financial, housing, recreation, employment, social, and community supports to meet individual needs; • has the right to fair and equal access to and choice from the range of CAMH treatments and services available (both clinical and non-clinical), and to culturally-based healing modalities (e.g., smudging, etc.), and to reasonable accommodations that are required to support their participation; • has the right to recovery oriented, trauma-informed and trauma based care, including support with experiences of abuse and other forms of trauma • has the right to collaborate in the development of a discharge plan with a housing option, and assistance in accessing outpatient supports and making referrals.
Ontario Shores Centre for Mental Health Sciences (Whitby)	<ul style="list-style-type: none"> • Respect for all individuals • Safety for all individuals through the: • Excellence for all individuals through the: • Right to quality services that comply with healthcare standards • Community for all individuals through the: • Right to be fully informed about all treatment options • Right to make an informed choice, and give informed consent

	to treatment
Providence Care Hospital (Kingston)	<ul style="list-style-type: none"> • This document reflects the input of patients, clients, residents, their families and the broader community. It is Providence Care’s commitment to treat all individuals with respect, dignity and compassion. • Right to be treated in a manner that recognizes my individuality and that respects my dignity, and cultural, ethnic, spiritual, linguistic and regional differences. • Right to receive support in meeting my recovery goals. • To me, this means I am an individual with my own feelings and needs, and that my dignity as a person must be respected by those who provide me care and services. • Right to communicate in confidence, receive visitors of my choice and consult in private with any person without interference. • Right to make choices and have all the information I need to make good choices. • Right to have my lifestyle and my choices respected.
Southwest Centre for Forensic Mental Health Care (St. Thomas)	<ul style="list-style-type: none"> • When you walk through our doors, we want you to know we value you as an individual - and hope our care surpasses your expectations. • Every patient has the right to make an informed choice and give informed consent to treatment
St. Joseph’s Healthcare (Hamilton)	<ul style="list-style-type: none"> • Respect patient’s individual identity, beliefs, history, culture and ability. Provide equal and fair access to the care and services, regardless of ability, race, ethnicity, language, background, place of origin, gender identity, sexual orientation, diagnosis, age, religion, socioeconomic status, education. • Core Value Four: Informed Decision Making Clients have access to reliable and current information about their health care options, in order to support informed decision making and active participation in care.
Waypoint Centre for Mental Health (Penetanguishene)	<p>To be treated fairly and with respect, regardless of your personal identity and circumstances, according</p> <ul style="list-style-type: none"> • We will take your experiences into account as we work with you to develop your recovery plan. • A variety of therapeutic activities to support your recovery including recreation, leisure opportunities, education, and employment support, as resources and availability permit • When a service or therapy you wish to use is not available at Waypoint, we will support you in your lawful choice to explore other resources in the community. • That you will be offered evidence-based treatments and be

	<p>informed of alternative treatments to education, as resources and availability permit.</p> <ul style="list-style-type: none">• if you are not well enough to understand or decide about treatment or research, a family member or a third party will make your decisions until you are well enough to decide for yourself. If this happens to you, you will be informed of your legal options.
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This theme alludes that each patient is unique and their voice and identity is unique and should not be treated as a homogenous identity in a hospital. It shows how everyone's experiences are different and implies that healthcare communication and relationships should be tailored to each person. The PDoVS highlight that institutional documents and the language used within them play a crucial role in shaping and reflecting the broader social and cultural understandings of patients and their identities. The act of naming something—a group, activity, or identity—carries a lot of meaning and history with it. These connotations and associations influence how people experience different environments or situations.⁵¹⁷ Identity and subjectivity extend beyond voice, culture, race, religion, sex, and age etc. to encompass how individuals perceive themselves in relation to, or in opposition to medical authority. In summary, this theme is relevant to my research as it explores how service user subjectivities and agency are constructed, whether as passive or active, recovering, and how they are interconnected with the dynamics between healthcare workers and patients within institutions as they navigate mental health, treatment, and decision-making about care.

⁵¹⁷ Rose, *Supra note 402* at 159

5.4 Theme 4 Law as Elusive

The final theme addresses how rights are invoked across the PDoVs. All the hospital PDoVs I analyzed make mention of patient rights, although most of these documents do not explicitly reveal or point to what legislative statutes oversee the rights being written. The PDoVs do however, invoke the rights as established for instance in the *Ontario Mental Health Act*⁵¹⁸, the *Health Care Consent Act*⁵¹⁹ and *Substitute Decisions Act*⁵²⁰ and *Privacy Legislation*⁵²¹ as well as the *Human Rights Code*⁵²². Hospitals infer a commitment to patient-centred care, transparency and informed decision-making in the realm of treatment and/or research. Patients are assured inclusion in treatment decisions, and comprehensive explanations, both verbal and in writing, are noted as important for recommended treatments and research projects. The data emphasizes a patient's right to be informed about treatment options, and to make choices in a way that is understandable to them. Privacy during treatment is discussed in all PDoVs and patients are guaranteed rights such as freedom from abuse, protection of personal freedoms, and the least restrictive environment. The document also outlines the right to access records, fair and equal treatment, and the ability to decline involvement in research without compromising access to care.

TABLE 6 Law as Elusive

Sites	Representative Data
Waypoint Centre for Mental Health (Penetanguishene)	<ul style="list-style-type: none"> • We will include people who receive care in treatment decisions. • That your consent to treatment or research can be withdrawn at any time, or as permitted by law. • That the results of assessments, diagnoses, treatments, and how

⁵¹⁸ Ontario. Ministry of the Attorney General. *Mental Health Act*, R.S.O. 1990, c. M.7.

⁵¹⁹ Ontario. Ministry of the Attorney General. *Health Care Consent Act*, 1996, S.O. 1996, c. 2

⁵²⁰ Ontario. Ministry of the Attorney General. *Substitute Decisions Act*, 1992, S.O. 1992, c. 30.

⁵²¹ Ontario. Ministry of Health and Long-Term Care. *Personal Health Information Protection Act*, 2004, S.O. 2004, c. 3, Sched. A.

⁵²² *Human Rights Code*, *Supra* note 470.

	<p>those treatments can affect you, will be carefully explained to you.</p> <ul style="list-style-type: none"> • That we will ask you about the effects of medications you have taken in the past, including any drug and alcohol use. • We will include people who receive care in treatment decisions. • you will be offered evidence-based treatments and be informed of alternative treatments to medication, as resources and availability permit. • That if you are not well enough to understand or decide about treatment or research, a family member or a third party will • To be treated fairly and with respect, regardless of your personal identity and circumstances, according to the vision, mission and values of Waypoint, the Ontario Human Rights Code and the Canadian Charter of Rights and Freedoms⁵²³ • Decisions until you are well enough to decide for yourself. If this happens to you, you will be informed of your legal options. • will support you in your lawful choice to explore other resources • the results of complaints.
St. Joseph's Healthcare (Hamilton)	<ul style="list-style-type: none"> • As a result, it is one of the few organizations in Canada that has embedded that philosophy into decisions on care, treatment and research since 2006.
St. Joseph's Health Care Group (Thunder Bay)	<ul style="list-style-type: none"> • Be provided information about my health, treatment options and consent to treatment in a way that I understand and at my request • Be provided information, resources and other supports to help me make decisions about my care • Be afforded privacy during treatment to the best extent possible • Provide my consent to participate and withdraw my consent and participation at any time during any engagement activity
Southwest Centre for Forensic Mental Health Care (St. Thomas)	<ul style="list-style-type: none"> • Every patient has the right to make an informed choice and give informed consent to treatment
Providence Care Hospital (Kingston)	<ul style="list-style-type: none"> • Right to be afforded privacy in treatment and in caring for my own personal needs • the right not to have my freedom limited any more than

⁵²³ Waypoint Centre for Mental Health Care (Penetanguishene), *Supra* note 176 at 1A.

Parkwood Institute (London)	<ul style="list-style-type: none"> absolutely necessary; • the right to “be treated with courtesy and respect and to be free from mental and physical abuse.”⁵²⁴ <hr/> <ul style="list-style-type: none"> • Every patient has the right to make an informed choice, and give informed consent to treatment. • Understand the nature of the care that is proposed • An explanation of the alternative care options and supports including no treatment • has the right to a choice of services, and will not be denied other options; • Right to make an informed choice, and give informed consent to treatment • No care shall be given without the patient’s voluntary informed consent, except in accordance with the law. • Consent must be for that particular treatment or plan of treatment. • Consent can be withdrawn at any time. • Information about the treatment must be provided in writing on request. • Every effort must be made to promote understanding and access to information about proposed treatments and supports. • Those considered incapable of making treatment decisions, has the right to be involved in the development of their plan of care and discharge planning. • Bill may be restricted by law or by order of a • The rights outlined in this Bill may be restricted by law • restraint except where permitted by law • has the right to records in accordance with the law • has the right to freedoms in accordance with the law
Ontario Shores Centre for Mental Health Sciences (Whitby)	<ul style="list-style-type: none"> • Right to be fully informed about all treatment options • Right to make an informed choice, and give informed consent to treatment • Right to have support person(s) as part of treatment
Centre for Addiction and Mental Health (CAMH) (Toronto)	<ul style="list-style-type: none"> • Right to direct treatment decisions. • has the right to protection from abuse, indifference, denial of care, retribution, punishment, and unjustified interventions; • has the right to the least restrictive environment and to be offered the • least intrusive treatment; • right to receive rights advice in accordance with legislated rights when decisions are made that impact liberty, when

⁵²⁴ Providence Care Hospital (Kingston), *Supra* note 474.

detained involuntarily, being found **incapable** of making decisions about treatment or property, or when a **Community Treatment Order** is issued/renewed;

- **right to challenge certain decisions** that impact their liberty (i.e., when they are involuntarily detained or found incapable of consenting to treatment or management of property);
- has the right to a **sexually safe environment** that promotes **privacy**, is respectful of intimacy needs and allows for healthy **sexual expression**, ensures patients have **access to private bedroom space**, and provides information on **contraception, safer sex, and the impact of treatments on sexuality**;
- has the right to **fair and equal access** to and choice from the range of CAMH treatments and services (both clinical and non-clinical), and to **culturally-based healing modalities** (e.g., smudging, etc.), and to reasonable **accommodations** that are required to support their participation;
- has the right to **express a preference in service providers and outpatient treatment teams**
- the perceived **problem, diagnosis** or condition, and **proposed treatment**; alternative options/treatments, including none; the likely **consequences of not having treatment**;
- if capable, must give voluntary, **informed consent before each treatment** or plan of treatment can commence and has the right to **withdraw that consent**
- unless found incapable, is **presumed to have capacity** to make treatment decisions;
- the **right to decline involvement in research**, where consent is sought, at any time without impact on access to care, treatment, or services.

This theme is pivotal within the context of this thesis as it elucidates the discourse surrounding patient rights in hospitals, incorporating references to legislation and underscoring subthemes such as power dynamics, administrative protocols, and regulatory compliance. The explicit function of these legal references within the PDoVs is to provide transparency regarding the foundational legal frameworks and principles that inform this discourse in these value statements. Consequently, patients become integral to the process of production and operationalization of the hospital's brand. The latent effects of these references are that they sustain the perception that institutions are committed to justice, particularly in discussions of

informed choice, the right to decline treatment, and access to information, as evidenced by the data. This raises critical questions about the clarity and enforceability of the rights delineated within the PDoVs and examines the extent to which these "rights" are disseminated and actualized into tangible patient experiences, entitlements, and outcomes within psychiatric settings.

Chapter 6 DISCUSSION

The broader connections between ‘mental health problems’ and political systems have now been well rehearsed by social epidemiologists. The dominant global politics in the twenty-first century has been neoliberal; that is to say based on globalized free market-driven economics with reduced expenditure on supportive welfare services⁵²⁵

In this chapter, I aim to synthesize the findings from this study (Chapter 5) and distil the insights and elaborate on their implications for my study's larger objectives of comparing analysis across the nine schedule healthcare institutions⁵²⁶. This study sought to address three primary inquiries regarding the Patient Declaration of Value Statements (PDoVs). Firstly, I identified and examined the discursive themes that appeared within the PDoVs, shedding light on the commonalities and differences across the institutions. Secondly, I sought to establish whether the identified themes within the PDoVs reflect a particular emphasis on human rights, the patient advocate office, or other mechanisms designed for the protection of patient rights. Finally, this research explored themes via empirical evidence related to patient voice, identity, and engagement as manifest within the PDoVs text narratives of the nine hospitals studied. This chapter is divided into four sections that support the following conclusions about the nine hospitals studied:

1. PDoVs demonstrate similarities in their messaging, particularly in participating and advocating for access of their healthcare services. Concurrently, they underscore the

⁵²⁵ Peter Beresford, *All Our Welfare: Towards Participatory Social Policy*, (Bristol, Policy Press (2016b)).

⁵²⁶ These nine facilities included: The Royal (Brockville), St. Joseph's Healthcare (Hamilton), Providence Care Hospital (Kingston), Parkwood Institute (London), Waypoint Centre for Mental Health (Penetanguishene), Southwest Centre for Forensic Mental Health Care (St. Thomas), St. Joseph's Health Care Group (Thunder Bay), The Centre for Addiction and Mental Health (Toronto) and Ontario Shores Centre for Mental Health Sciences (Whitby)

importance of patients assuming responsibility and displaying respectfulness during their hospital stays;

2. Patient subjectivity is cultivated as a singular entity, emphasizing a narrative of self-governance and a recoverable self, while exhibiting an apparent lack of historical contextualization;
3. Within PDoVS rights are delineated, however, a discrepancy arises between the assertion of rights and the actual accessibility and comprehension of such rights, further exacerbated by the waning prominence of the PPAO;
4. There is a notable absence of theoretical frameworks concerning law, disability and psychiatric disability (Mad Studies) discourse in the PDoVs. These frameworks are frequently marginalized or overlooked, rendering them an underexplored area within the promotion of these PDoV efforts.

6.1 Responsibilization and Respect

The current read on values and narratives within PDoVs has patients bound by presumptive agreements wherein they are expected to uphold responsibilities (theme 1) not only to the hospital, fellow patients, and the environment, but also to actively engage in the healthcare process as civic actors. A trend emerging in these discourses exemplifies a progression towards an "enterprising self," characterized by the combination of agency and reflexivity. The enterprising self-engages in self-calculation and self-directed actions aimed at self-improvement.

This concept of enterprise reflects a mode where effective governance is contingent upon individuals' abilities to govern themselves⁵²⁷.

From a disability rights perspective, examining the PDoVs and the values they embody also reveal a complex interplay between the “carceral layers”⁵²⁸ and therapeutic elements in psychiatric sites. There are not only the responsibilities that patients must uphold but also the opportunities afforded to them for (supposed) meaningful participation as civic actors. This raises questions regarding the accessibility of such participation and the extent to which psychiatric patients more specifically fully understand their experiences, including facets of their detention and associated human rights.⁵²⁹ This multifaceted dynamic considered within the broader goals of legislative requirements, such as those enacted by the (Accessibility for Ontarians with Disabilities Act) AODA⁵³⁰ or the *Ontario Human Rights Code*⁵³¹ for people with disabilities, also prompts consideration about what supports for participation are required, resourced, or even acknowledged. This is particularly salient in scenarios where psychiatric initiatives encounter resistance from “participatory patients.” Markham, a forensic patient advocate, has written extensively about the perspectives of patients who experience the most restrictive types of detention: the forensic system. She notes that patients may encounter implicit

⁵²⁷ Nikolas S Rose, *Inventing Our Selves : Psychology, Power, and Personhood*. (Cambridge: Cambridge University Press, 1996) at 154.

⁵²⁸ Drawing from Virve Repo’s work, the concept of “carceral layers” elucidates the complex, multilayered ontologies inherent in carceral spaces, enhancing our comprehension of how such spaces are formed within institutions of care. Virve Repo “Carceral layers in a geropsychiatric unit in Finland” (2019) 101:3 *Geografiska Annaler: Series B, Human Geography*

⁵²⁹ Please see: P.S. v. Her Majesty the Queen, 2013 ONSC 2970 as a case in point; PS was civilly committed under Ontario's *Mental Health Act*. Despite being deaf with limited communication skills, he spent 19 years at Waypoint Centre for Mental Health Care (Penetanguishene), without treatment, largely warehoused (gated) in maximum security against recommendations.

⁵³⁰ *Accessibility for Ontarians with Disabilities Act*, 2005, S.O. 2005

⁵³¹ *Human Rights Code*, *Supra* note 470.

coercion through pressure to meet therapeutic goals in which they have had no role in establishing, and for which they receive inadequate, if any, support.⁵³²

Within the PDoVs, there is a presumption that mere vocalization ensures genuine listening, reciprocal respect, especially within health contexts where the structure of institutions is to impose interpretations upon individuals via clinical assessment and legal requirements of documentation⁵³³. The contemporary framing of concepts such as "participation," "respect," and "responsibility" in PDoVs highlights the nuanced juxtaposition of these terms. This evolution in the language underscores a dual emphasis: on the one hand, there is a reinforced commitment to accountability and personal responsibility in the context of patient care; on the other hand, these notions are interwoven with the ongoing patient reliance on the dependability of care and service provision. And as such, you can have PDoVs that delineate that patients can “participate as part of the healthcare team in developing your plan of care” but that they also need to “be mindful of the healthcare team’s obligations to other patients.”⁵³⁴

An exploration of respect within the hospital milieu necessitates an examination of how the invocation of respect may serve to mute and redirect voices of dissent. Does respect imply deference? I would argue that in many ways, the lexicon across PDoVs is not shifting whether patients are respected or not, but more so shaping and guiding patients and other stakeholders to *adhere* to a culture of respect with very stringent civility and propriety standards. This phenomenon is not novel within institutional contexts. “Respectability” and its opposite,

⁵³² Sarah Markham, "The totalising nature of secure and forensic mental health services in England and Wales." (2021) 12 *Frontiers in psychiatry*.

⁵³³ Anna P Goddu, et al. "Do words matter? Stigmatizing language and the transmission of bias in the medical record." (2018) 33 *Journal of general internal medicine*.

⁵³⁴ St. Joseph’s Healthcare (Hamilton). *Supra* note 473.

degeneracy, were integral elements of the ideological discourse in the nineteenth century, reflecting dynamics of dominance and subjugation. “Respectability” served as a marker of belonging to the middle class and legitimized the authority to exert control over others, particularly those deemed as degenerate⁵³⁵. As an illustration, in a dispute between the Union and the Ottawa Hospital regarding a new dress code policy that mandated employees to conceal large tattoos and remove excessive body piercings, the hospital invoked the *ECFAA* to justify its stance:

Hospitals are required by the *Excellent Care for All Act, 2010*, to constantly seek improvement in the quality of health care they deliver, and cannot sit back and wait for evidence of patient complaints before making changes, the employer argues. Boosting the professional image of employees improves patient confidence, and that improves the quality of health care, the hospital says. In this grievance, the union seeks to have individual rights trump the collective good in a system that must serve all patients equally, including those patients who are concerned about the professionalism of employees with tattoos or piercings.⁵³⁶

This approach disregards diverse identities and choices, effectively policing employees' expression to conform to institutional standards. Concepts like dignity and respect though well meaning, introduce complexities influenced by cultural, societal, and individual perspectives, potentially leading to biased clinical and legal interpretations and decisions. Moreover, disparities in the application of these principles across different individuals or identity groups within the medico- legal system underscore underlying inequalities as read in *Conway v Darby*.⁵³⁷ Further, Daley and Pilling have explored the ways in which psychiatric theories and

⁵³⁵ Mary Louise Fellows and Sherene Razack. "The race to innocence: Confronting hierarchical relations among women." (1997)1: *J. Gender Race & Just.* at 346.

⁵³⁶ *Ottawa Hospital v Canadian Union of Public Employees, Local 4000*, 2013 at 28.

⁵³⁷ For example, please see: *Conway v. Darby, 2008* CanLII 54773 (ON SC) wherein, the physician testifies that his patient suffered from a psychotic disorder, attributing it partly to the patient's display of mistrust and suspicion towards others' motives within the system, coupled with a belief in experiencing pervasive racism, extending to the entirety of the Canadian population

practices influence how distress is understood and categorized according to hypersurveillance of gender norms and documentation of physical appearance.⁵³⁸

Power dynamics inherent in hospitals and legal proceedings such as consent and capacity board hearings, or Ontario Board hearings, where patients have unequal influence, further complicate the consistent application of “dignity and respect” often resulting in mistreatment, ableism and sanism. The impetus behind advancing narratives of respect and respectability, underscores the mechanisms through which deference is both expected and subtly imposed, while individual self-agency is simultaneously promoted and decoupled from broader objectives such as collective inquiry and resistance to disempowering practices. This raises critical questions about how “collective disrespect” (or epistemic injustice as previously mentioned)⁵³⁹ can be measured and addressed within an institutional context.

A culture of respectability politics is about acquiescence to dominant norms and willingness to integrate into dominant structures, while disrespectability politics would be the rejection of assimilation as well as the critique of dominant norms.⁵⁴⁰ Responsibilization, participation and respect are linked themes that, on the one hand, push for an environment of care, while on the other hand, reinforce paternalism and a potential suppression of expression and other emotions which could lead to punitive clinical responses. Given PDoVs are based on the “engagement of patients” in their development, at a theoretical level this engagement—remains unclear or not well-defined.

⁵³⁸ Andrea Daley, Merrick D. Pilling, eds. *Interrogating psychiatric narratives of madness: documented lives*. (Cham: Springer Nature, 2021).

⁵³⁹ Patricia Hill Collins, *Supra* note 373 at 118.

⁵⁴⁰ Margot Dazey, “Rethinking Respectability Politics” (2021) 72:3 *The British Journal of Sociology*.

6.2 Patient Subjectivity - No “Self” Left Behind

The third theme, patient subjectivity, underscores the uniqueness of each patient self, highlighting “patient’s individual identity, beliefs, history, culture and ability”⁵⁴¹. The data argue how everyone's experiences are different and suggests that healthcare communication and relationships should be tailored to each person. Identity emerges as a significant focal point in the discussion, emphasizing the acknowledgment and respect for individual identities, beliefs, and cultural backgrounds. However, a critical lens prompts questions about how these principles of racism, sexism, culture, sexual identity etc. are operationalized in practice. As queried in other research, the definition of a patient perspective, including the necessary level of patient engagement and the diversity of views required to establish it, remains unclear⁵⁴² and in my summation, lacks a theoretical framework.

Discussion of “choice”⁵⁴³ is apparent in the PDoVs emphasizing the importance of patients having a “voice” in their treatment plans across PDoVs. Yet, it is unclear whether genuine collaboration in decision-making exists or if it remains a token acknowledgment. “Informed decision-making” also stands out as a dominant principle in all nine hospitals, highlighting the need for patients to have comprehensive information about their healthcare options but institutions do not have, or do not resource, the ability to truly assist patients with the necessary information for informed choices per se, as consent requires physicians sharing information in order for a patient to know what they are consenting to.⁵⁴⁴ These debates about informed choice,

⁵⁴¹ St Joseph's Healthcare (Hamilton) Supra note 473.

⁵⁴² Rowland and Kumagai Supra note 127.

⁵⁴³ The term "choice" is most commonly employed, whereas "consent" is primarily referenced in relation to Privacy/Personal Health Information disclosures or in the context of consenting (or declining) to participate in research. However, "consent" as a term specifically designating agreement to treatments offered is not readily apparent in many instances.

⁵⁴⁴ Please see: *Starson v Swayze*, 2003 SCC 32

and/or the impacts of not medicating/treating patients have been longstanding since the early days service user/survivor activism wherein patients (once detained) are often set up with the “proposition to choose their own hell”.⁵⁴⁵ Overall, when viewed through a critical and Mad Studies lens, the data prompts reflection on two analysis: 1) what is the realistic implementation and effectiveness of principles such as choice within mental health institutions when there continues to exist barriers to access to advocacy and justice⁵⁴⁶ and, 2) what clinical skills are fostered for respecting voice/identity choices (particularly resistant identities) while addressing individuals who are in distress and appear to lack decision-making capacity.⁵⁴⁷

In the PDoV data, hospitals also leverage notions of hope for health as a means to shape the subjectivities of patients, inducing assimilation to the abstract values from PDoVS into their sense of self. This process entails prescribing notions of health and recovery, essentially instructing individuals on what they should desire, and how they should envision their hopes for wellness (separate from any other contextual issues related to the social determinants of health). Rabinow and Rose speak about “modes of subjectification” by way of encouraging individuals to work on themselves under certain forms of authority (bio-power), and influenced by what is considered true, by means of practices of the self.⁵⁴⁸ I reference this example to contextualize it as per my literature review, particularly concerning the discourse on recovery and its emergence

⁵⁴⁵ Please see: “Carla McKague” in Irit. Shimrat, *Call Me Crazy: Stories from the Mad Movement* (Vancouver: Press Gang, 1997) at 71.

⁵⁴⁶ Tess C Sheldon, Karen R Spector & Mercedes Perez, "Re-Centering Equality: The Interplay between Sections 7 and 15 of the Charter in Challenges to Psychiatric Detention" (2016) 35:2 NJCL 193.

⁵⁴⁷ Mohammed Abouelleil Rashed, “The Identity of Psychiatry and the Challenge of Mad Activism: Rethinking the Clinical Encounter” *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, (December 2020) 45:6.

⁵⁴⁸ Paul Rabinow & Nikolas Rose, "Biopower Today" (2006) 1 *Biosocieties* 197.

in the health sector. This is illustrated for example, in statements such as the PDoV from Waypoint which states that every person can expect:

A variety of therapeutic activities to support your recovery including recreation, leisure opportunities, education, and employment support, as resources and availability permit.⁵⁴⁹

Their PDoV titled, "Declaration of Recovery Values," despite its ironic title, essentially instills and dictates to patients that they will recover, or, in other words you *are who I say you are*. But this too, is reined in as the same document states,

When a service or therapy you wish to use is not available at Waypoint, we will support you in your lawful choice to explore other resources in the community.⁵⁵⁰

This quote foreshadows the inherent limitations of the provisions offered, a phenomenon not exclusive to Waypoint. For instance, CAMH acknowledges that certain rights may be restricted by factors such as legislation, court orders, resource availability, working in good faith⁵⁵¹.

To genuinely build trust in the statements found in PDoVs, which highlight the importance of valuing voice, individuality, choice, options and identity, it becomes essential to inquire why these declarations frequently exhibit significant similarities in tone, language. Additionally, a question beyond the scope of this study is to examine how patients are constructed in relationship to disciplines, frameworks, and goals in healthcare delivery. In this study context, informed consent, voice, recovery goals, identity mean adherence to clinical recommendations. Service users do not participate or influence team meetings or academic conversations regarding treatments; rather, they are informed about treatments and care milieus

⁵⁴⁹ Waypoint Centre for Mental Health Care (Penetanguishene), *Supra* note 176 at 2j.

⁵⁵⁰ *Ibid*

⁵⁵¹ CAMH (Toronto) *Supra* note 481.

post facto. While some hospitals did have representation of patient groups on their site, the efficacy of their involvement at the policy level is unclear.

6.3 Law as Elusive

The final theme highlights the incongruous nature of patient rights across various PDoVs. All the hospital PDoVs make mention of patient rights, however, these rights do not explicitly reveal what legislative statutes oversee the rights being discussed and as such, both promise these rights but do not explicitly explain where they are positioned, how to access advocacy support or appeals. Although hospitals allude to rights under the *Charter*,⁵⁵² the *Human Rights Code*,⁵⁵³ *Freedom of Information and Protection of Privacy Act*,⁵⁵⁴ the *Mental Health Act*⁵⁵⁵ and the *Criminal Code*⁵⁵⁶ these are inconsistent across the sites examined and there is no imperative to have rights enforced thus leaving them somewhat elusive and unprotected.

The efficacy of patient rights in these hospital settings is contingent upon numerous factors including structural design, the delineation of enumerated rights, staff education on rights infringements, the interplay with complementary legal frameworks, and the ability to address and ameliorate systemic healthcare challenges⁵⁵⁷. At the heart of this matter lies the way in which patients give voice to their concerns, whether or not they weave their words into the language of rights⁵⁵⁸. Absent a dependable and *ongoing* enforcement mechanism, patient rights are

⁵⁵² *Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982*, being Schedule B to the Canada Act 1982 (UK), 1982, c 11 [Charter]

⁵⁵³ *Human Rights Code*, *Supra* note 470.

⁵⁵⁴ *Freedom of Information and Protection of Privacy Act*, RSO 1990, c F.31.

⁵⁵⁵ *Ontario Mental Health Act* *Supra* note 287.

⁵⁵⁶ *Criminal Code* (R.S.C., 1985, c. C-46).

⁵⁵⁷ Colleen Flood and Kathryn May. *Supra* note 213.

⁵⁵⁸ For a discussion on how the recursive nature of rights and identity affect one another over time please see: David M Engel, and Frank W. Munger. *Rights of inclusion: Law and identity in the life stories of Americans with disabilities*. (Chicago: University of Chicago Press, 2003).

ineffectual, and as Flood remarks, is a proverbial "toothless tiger."⁵⁵⁹ The intermingling of "rights" and "values" terminology within PDoVs is interesting but confounding, potentially allowing hospitals to interpret and apply the PDoVs in a more flexible manner – either literally via rights protections or symbolically via declarations.

While rights encompass legal entitlements that patients possess, which can be enforced by law, in contrast, values represent beliefs or principles deemed important and desirable. Unlike rights, values are subjective and can vary across individuals and institutions and can also foster particular kinds of liminality, or spaces that are “states of exception” within the structures of a psychiatric institution.⁵⁶⁰ In these psychiatric units or spaces, accountability regarding the restriction of liberty can be violated without proper oversight⁵⁶¹. This aspect holds significance within the scope of my research as one of its objectives was to scrutinize the prevailing modalities through which rights discourse are diffused and disseminated within hospital environments. I sought to explore the nexus between the PDoV phenomenon and the established lineage of service user embodied knowledge and advocacy access such as the psychiatric patient

⁵⁵⁹ *Ibid*

⁵⁶⁰ Jean Daniel Jacob, and Thomas Foth. "Expanding our understanding of sovereign power: On the creation of zones of exception in forensic psychiatry" (2013) 14:3 *Nursing Philosophy* 178-185.

⁵⁶¹ For example, at CAMH and pursuant to section 672.81 (1) of the *Criminal Code* - At an annual disposition order review hearings of forensic patients, the Ontario Review Board (ORB) is tasked with assessing whether the accused individual still presents a significant risk to public safety. If there is evidence of risk, the ORB must deliberate on the most suitable course of action, choosing between a conditional discharge or a detention order, accompanied by appropriate conditions. The disposition must be the least onerous and least restrictive with the consideration of safeguarding the public's safety. However, if a forensic client is placed in the Structured Observation and Treatment Unit(SOTU) in essence, a seclusion unit or suite that is considered “treatment” and not subject to provisions of the Code that deal with issues of liberty given it is not a forensic unit, but rather a mixed-use unit with a high degree of supervision.

advocate office particularly as the protections within the constitution for individuals detained in hospitals remains precarious.⁵⁶²

As mentioned, the *ECFAA* received Royal Assent on June 8 2010. On June 29th 2011 the Ontario Ministry of Health and Long-Term Care (MOHLTC) announced that the Canadian Mental Health Association Ontario (CMHA) would be taking control of the government's Psychiatric Patient Advocate Office (PPAO). There had been no public announcement and no consultation. I am establishing here the paradoxical situation of advocating for increased accountability, while concurrently diminishing the effectiveness of the office tasked with safeguarding patient rights across various domains, including hospitals, education, and legal proceedings such as inquests such as the PPAO office did. Hence, scrutinizing the PDoVS and asking how the government's decision-making and oversight of healthcare portfolios contrasts with the practical deliberations and steering in which patients/service users can actively participate to effect meaningful change in the system, such as influencing policies and intervening in potentially complex legal questions and human rights issues.

6.4 Theory and the Return to Mad Praxis

Although this study primarily focused on nine-hospital settings, initiatives aimed at promoting patient-centred care, patient participation, and engagement have been widely adopted across all hospitals, with the overarching aim of fostering transformations within these institutions. Efforts are being made to secure time, resources, and funding to support projects that

⁵⁶² Sheldon, *Supra* note 61.

seek to involve patients in “co-production” processes.⁵⁶³ But, a notable gap in these initiatives lies in the lack of explicit articulation of the theoretical frameworks informing the implementation of such projects by service providers. While service users have ardently advocated for inclusion in system development, four decades later, such participation has not been adequately grounded in theoretical frameworks. It is important to recognize that the current push for participation and engagement initiatives are not methodological approaches. An essential aspect of promoting participation lies in the establishment of mechanisms, accountability frameworks, and the pursuit of systemic and human rights-oriented reforms that are able to include not just singular individuals, but theoretical frameworks. Scholars within the field of Mad Studies, both academically and at grassroots levels, express concern that institutions may superficially involve patients in committees or advisory roles without addressing the underlying norms and practices that hinder individuals' flourishing within these institutions or industries.⁵⁶⁴

While other theoretical frameworks, such as those addressing anti-racism, equity, diversity, and inclusion (EDI), have gained traction (particularly post George Floyd)⁵⁶⁵ and are somewhat apparent through (some) hospital PDoVS in their statements about “race, culture, colour, religion, sex, age, mental or physical disability, class/economic position, sexual orientation, gender identity”⁵⁶⁶, there is minimal incorporation of frameworks related to LGBTQ2S and anti-

⁵⁶³ Gillian Mulvale and Glenn Robert “Special Issue- Engaging Vulnerable Populations in the Co-Production of Public Services” (2021). 44:9 International Journal of Public Administration.

⁵⁶⁴ Lori E Ross, et al. “I Will Play This Tokenistic Game, I Just Want Something Useful for My Community’: Experiences of and Resistance to Harms of Peer Research.” (2023) 33.5 Critical public health.

⁵⁶⁵ Allison Brown, Emmanuelle Auguste, Favour Omobhude, Naomie Bakana, and Javeed Sukhera "Symbolic solidarity or virtue signaling? A critical discourse analysis of the public statements released by academic medical organizations in the wake of the killing of George Floyd." (2022) 97:6 Academic Medicine.

⁵⁶⁶ Parkwood Institute (London). *Supra* note 475 at 4

Indigenous racism. This absence underscores the need for a more comprehensive integration of theoretical perspectives, particularly those concerning disability, within healthcare initiatives aimed at enhancing patient care and participation.

As illustrated in the PDoVs, the Ontario healthcare system encourages patients to play a role and participate and work cooperatively with medical providers and other actors (i.e. other patients and families). The PDoV content places emphasis on showing patients as active participants⁵⁶⁷ in their care rather than as passive recipients of it but, the content across sites also reveals latent and “baked in” vulnerability: patients' opinions must be heard, and they must be treated with courtesy and respect and to “be free from mental and physical abuse”⁵⁶⁸. Power imbalances are present in PDoVs and their assumed frameworks, even if they are not clearly stated. These imbalances often reveal themselves through contradictions in the idealized and symbolic statements of these systems. Although the crafting of inspirational values documents may not, in itself, pose an inherent issue, my contention is that history reveals a recurring pattern: we find ourselves revisiting the classic liberal idea that individuals possess an equal opportunity to engage and reap the rewards of equality. This reaffirmation of highlights a significant continuity in an ongoing ideological struggle for genuine equity.⁵⁶⁹ The PDoV statements and engagement initiatives also highlight the elusive character of law and more

⁵⁶⁷ The Royal (Brockville), *Supra* note 479.

⁵⁶⁸ Providence *Supra* note 474.

⁵⁶⁹ Peter Beresford, *Participatory Ideology- From Exclusion to Involvement* (Bristol University Press, 2021)

importantly, the somewhat decontextualized and apolitical nature of the intent of *ECFAA*⁵⁷⁰ and PDoVs given the complex, ableist⁵⁷¹, colonial⁵⁷² domain of psychiatric medicine.

As discussed in my literature review, Mad Studies, as an interdisciplinary field, critically analyzes the ways in which madness is constructed within these institutional settings and via traditional psychiatric discourse and practices. By investigating how patients are portrayed and narrated within the PDoVs this research aligns with the core concerns of Mad Studies and service users in general, which asks deeper questions about power and autonomy, consent and inclusion and epistemology more broadly⁵⁷³. Understanding the contemporary narratives and roles assigned to patients within institutional settings, as well as the potential biases and the assumption that all service users and patients have equal opportunities to engage with and benefit from PDoV projects, to some extent, mitigates the perceived complexity of addressing systemic ableism and sanism. This assumption potentially underestimates the substantial effort still required to confront these issues, within hospitals (which is still carceral like spaces) and within judicial decisions and court proceedings. These disparities, contribute to the ongoing dialogue within Mad Studies about epistemic injustice⁵⁷⁴ and the need for ongoing, intellectual, pedagogical, and political interventions that advance understanding about medicine, healthcare economics and law. In essence, this research adds a theoretical scholarly contribution to the field of Mad Studies by addressing issues of power, representation, and autonomy within healthcare

⁵⁷⁰ *Excellent Care for All Act*, *Supra* note 1.

⁵⁷¹ Psychiatry clinicians themselves discuss the embedded challenges and ableism faced by medical school applicants with disabilities. Please see: Lisa M Meeks and Christopher Moreland. "How Should We Build Disability-Inclusive Medical School Admissions?" (2021) 23:12 *AMA Journal of Ethics*.

⁵⁷² Suman Fernando, *Institutional Racism in Psychiatry and Clinical Psychology: Race Matters in Mental Health*. (Cham, Switzerland: Springer Berlin Heidelberg, 2017).

⁵⁷³ Russo and Beresford *Supra* note 328.

⁵⁷⁴ Fricker *Supra* note 364.

systems, and access to justice which are still central to the field's objectives of challenging violence and structural biases obstructing the rights of service users.

Chapter 7 CONCLUSION

*As a methodology, advocacy research is pitted against the practices of democratic elitism*⁵⁷⁵

This research examined the discursive themes present across the Patient Declaration of Values (PDoVs) in nine Ontario facilities which receive services from the Ontario Psychiatric Patient Advocate office (PPAO) on their sites. As discussed, given that the *ECFAA* requires that all Ontario hospitals engage patients in the development of PDoVs, this research examined what themes appear across these PDoVs, how they manifested a focus on human rights, the patient advocate office, or other mechanisms for rights protection and finally, how these themes related to patient voice, identity and engagement.

7.1 Summary of Findings

When the *ECFAA*⁵⁷⁶ was adopted, it garnered media attention and initial scholarly discussions that highlighted its aspirations.⁵⁷⁷ It quietly passed in the legislature, while concerns continued to be expressed/debated about other government projects such as the Local Health Integration Network (LHINs)⁵⁷⁸ which was, consuming 60 percent of the total provincial healthcare budget and involving numerous highly public consultations throughout the province.⁵⁷⁹ All political parties in Ontario criticized the LHINs, with calls for overhaul or

⁵⁷⁵ Frank Fischer. *Citizens, Experts, and the Environment : The Politics of Local Knowledge*. Durham, (NC: Duke University Press, 2000) at 18.

⁵⁷⁶ *Excellent Care for All Act*, *Supra* note 1.

⁵⁷⁷ Please see: G. Ross Baker and Anu MacIntosh-Murray. "Governance for Quality and Patient Safety: The Impact of the Ontario Excellent Care for All Act, 2010." (2012) 15 SP3 *Healthcare quarterly* (Toronto, Ont.) and Karen Born and Andreas Laupacis. "Public Engagement in Ontario's Hospitals--Opportunities and Challenges." p (2012) 15 *Healthcare quarterly* (Toronto, Ont.)

⁵⁷⁸ Richard Mackie, "Ontario to offer 'health-care continuum'" *The Globe and Mail* (Jul 9, 2004) pg. A6.

⁵⁷⁹ Carey Doberstein, *Distributed Democracy : Health Care Governance in Ontario* (Toronto: University of Toronto Press, 2020).

abolition⁵⁸⁰ due to declared flaws in accountability and community engagement.⁵⁸¹ This is significant as the emergence of the *ECFAA*⁵⁸² was born amidst the prevailing political landscape that emphasized more accountability and increased consultation and it was covered in many media stories discussing that compensation for CEOs should be tied to performance accountability outcomes.⁵⁸³ One journalist captured the *ECFAA*'s⁵⁸⁴ fiscal intentions early on by identifying that the long-term goal was a shift toward a "patient-based" funding model, where hospitals rely less on global budgets and more on payments tied to the number of successfully treated patients, encouraging competition in high-density areas.⁵⁸⁵

The palpable sense of "competition" had already been noted in service user communities and discussed in provincial deliberations concerning the potential jeopardy faced by consumer/survivor initiatives and service user organizations, which could face the prospect of dissolution or amalgamation.⁵⁸⁶ As mentioned in my literature review, service user/survivor initiatives were once initiated because service users themselves advocated to have organization and representation on Boards, committees etc. on their own terms. In the midst of changes in how healthcare has evolved, particularly post Covid, with more partnerships with private

⁵⁸⁰ Premier Doug Ford's government also criticised and has since dismantled LHINs through the *People's Health Care Act* (2019), centralizing authority under Ontario Health. This has also had implications for how advocacy is managed.

⁵⁸¹ Doberstein *Supra* note 572 at 5-10.

⁵⁸² *Excellent Care for All Act*, *Supra* note 1.

⁵⁸³ Karen Howlett, "Hospital CEO pay packets to go under microscope". *The Globe and Mail* (Apr 1, 2011) p A12.

⁵⁸⁴ *Excellent Care for All Act*, *Supra* note 1.

⁵⁸⁵ Adam Radwanski, Health Care: Ontario Hospital CEOs Are Not The Targets *The Globe And Mail* (May 11, 2010) at A8

⁵⁸⁶ Ontario, Legislative Assembly, *Official Report Journal of Debates* (Hansard), 38th Parl.2nd Session, (15February 2006) at SP562 (Shelley Martel)

companies, smaller government involvement, and spending cuts⁵⁸⁷ there is a growing concern about access to mental health care, especially for youth.⁵⁸⁸ This phenomenon underscores the inherent tensions between the longstanding advocacy efforts of activists and patient groups dating back to the 1970s, and the formidable challenges engendered by resource constraints.

Incorporating the perspectives of those affected by policies and practices, aligns well with the idealised consumer-focused approach of neoliberalism but as Rose and Beresford note, this idea of ‘customer is king’ and involving patients in hospital initiatives differs significantly from the sharing of power that motivated service user involvement in the first place. Service users are increasingly emphasizing the importance of contributing to substantive change, rather than merely serving as symbolic figures that allow institutions to project an image of progressiveness and inclusivity.⁵⁸⁹ This is particularly salient in a contemporary context where institutions prioritize maximum efficiency and cost-cutting measures.⁵⁹⁰ The tension between these priorities is not lost on service users, who are acutely aware of the underlying dynamics at play.⁵⁹¹

My argument in this research posits that PDoVs along with their purported promise of engagement and aspirations of equity contribute to sustaining a particular mythology. This mythology upholds the notion that such mechanisms are inherently democratic and inclusive,

⁵⁸⁷ Janna Klostermann, Fighting privatization & austerity in Ontario healthcare March 1, 2022. Ontario Health Coalition online: <https://www.ontariohealthcoalition.ca/index.php/fighting-privatization-austerity-in-ontario-healthcare> [https://perma.cc/2B2X-RQRT].

⁵⁸⁸ Maria Chiu Evgenia Gatov, Kinwah Fung, Paul Kurdyak, and Astrid Guttmann, “Deconstructing The Rise In Mental Health-Related ED Visits among Children and Youth in Ontario, Canada: Study examines the rise in mental health-related emergency department visits among children and youth in Ontario.” (2020) 39.10 Health Affair.

⁵⁸⁹ Nev Jones, Kendall Atterbury, Louise Byrne, Michelle Carras, Marie Brown, and Peter Phalen, "Lived experience, research leadership, and the transformation of mental health services: building a researcher pipeline." (2021) 72: 5 Psychiatric Services.

⁵⁹⁰ Diana Rose and Peter Beresford, "PPI in psychiatry and the problem of knowledge" (2024) 24.1 BMC psychiatry at 4.

⁵⁹¹ Ross et al. *Supra* note 560.

while obscuring underlying power dynamics and structural limitations. The key takeaways from this work are that PDoVs resonate with a fundamental liberalist assumption that psychiatric service users are patients, divorced from any body-politic and that an equal distribution of services/healthcare is just around the corner. As individuals divorced from a group-politic or identity other than a medical one (as patient with one diagnostic label or another) the PDoVs advocate for access to healthcare while advising patients to embrace responsibility and respect. In shaping patient identity, they point towards a narrative of self-governance, the pursuit of recovery, while at the same time floating above the weight of a troubled historical context that remains bereft of substantial reparation. Rights are articulated, but there is a noticeable gap between their declaration and their tangible accessibility and understanding, a gap that grows wider as the Psychiatric Patient Advocate Office's influence has waned. The absence of discourse on psychiatric disability in these frameworks is striking, leaving these crucial perspectives marginalized and largely unexplored in the broader conversation in day-to-day operations of the *ECFAA*⁵⁹² and more importantly the annual reporting to the government. This research addressed the questions through a detailed examination of the PDoV text and a critical review of the language and embedded assumptions relevant to our current socio-political context—one in which service users have minimal access to strong advocacy mechanisms beyond the hospital patient complaints office, which, notably, functions under the purview of the hospital administration.

7.2 Implications

An implication and consideration for thinking through the PDoVS data pertains to the intricate mechanisms by which institutional entities regulate patient participation. Institutions

⁵⁹² *Excellent Care for All Act*, *Supra* note 1.

exercise considerable authority in orchestrating the composition of committees, focus groups, and the formulation of research inquiries – there is ample evidence to support this in the Mad Studies and disability literature. Hospitals not only select the patient participants but also dictate their modes of involvement and the specific agenda items they address. It is highly plausible that hospitals, if they engage in this process at all, would exercise discretion in choosing which patients contribute to PDoVs development and would likely remunerate them modestly via honoraria⁵⁹³. Thus, the fundamental reality is that institutions essentially subsidize the feedback that aligns with their predetermined objectives. In some ways, these new encouragements for engagement resemble the historical industrial therapy regimes where patients were rewarded for work assignments and performed essential institutional tasks, (such as doing laundry, ashtray cleaner linen folding)⁵⁹⁴ to bolster the function of institutions themselves.⁵⁹⁵

The observed parallels between historical and contemporary efforts to responsabilize and include patients warrant further scholarly exploration. Similarly, the manner in which the current governmental and institutional milieu exemplifies a form of “rational ignorance” also represents a fertile area for future research.⁵⁹⁶ Here, I use the term to describe how those in power deliberately choose to remain uninformed about decades of contributions from psychiatric disability perspectives. Added is the belief that the costs of educating, improving curricula, or investing in alternative research are perceived as outweighing the benefits of maintaining

⁵⁹³ Change Foundation. "Should Money Come Into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants" (Toronto: The Change Foundation: 2015).

⁵⁹⁴ For example please see: Toronto Star, “Eskimo souvenirs at 999 Queen” (Toronto Star, May 5, 1965) at 20.

⁵⁹⁵ Geoffrey Reaume, *Remembrance of Patients Past: Life at the Toronto Hospital for the Insane, 1870-1940*. (University of Toronto Press, 2009).

⁵⁹⁶ American economist Anthony Downs first introduced the concept of rational ignorance in his 1957 book, *An Economic Theory of Democracy*. Rational ignorance theorizes why many voters don't invest time in learning about candidates or parties. The perceived value of becoming informed does not justify the resources required.

privilege and the institutional status quo.⁵⁹⁷ This phenomenon has been evident within other groups and movements⁵⁹⁸ and I contend that it is equally relevant here. As such, the analytical objective in my research has been to “keep the institution in view”⁵⁹⁹ to elucidate how the state and institutional framework currently delineate the conditions of experience and legal subjectivity for service users.

The argument presented herein is especially significant amidst ongoing discourses on reparative justice⁶⁰⁰ which highlight the imperative of inclusive historiographical narratives in understanding the complexities of the past. These discussions emphasize the necessity of a reparative historical framework to adequately address both historical and contemporary injustices. Law intersects with these themes by providing the frameworks for pursuing reparative justice, legitimizing inclusive narratives, shaping patient rights in healthcare, and influencing the content and implications of legal education. Yet, this is easier said than done, and these objectives are replete with challenges and they reveal a profound irony: the endeavour to rectify inequities through the institutionalization of practices that center the patient’s voices/concerns in healthcare (through PDoVs for example) is situated within a broader context where invalidating forces strive to simultaneously efface history, curricular content, and other forms of contentious knowledge from service users and Mad Studies itself.

⁵⁹⁷ Anne-Marie Gagné-Julien, "Medicalization, Contributory Injustice, and Mad Studies." (2022) 32:4 Kennedy Institute of Ethics Journal at 401

⁵⁹⁸ For instance, please see: Anna Cook, “Recognizing Settler Ignorance in the Canadian Truth and Reconciliation Commission.” (2018) 4:4 6 Feminist Philosophy Quarterly. Charles W. Mills. “White Ignorance.” In Race and Epistemologies of Ignorance. Eds. Shannon Sullivan and Nancy Tuana. (New York: SUNY Press. 2007).

⁵⁹⁹ In her essay, "Keeping the Institution in View," Liz McCoy provides a valuable examination of the significance of research methods that attentively monitor institutional dynamics. See: Liz McCoy, “Keeping the Working with Institution in View: Interview Accounts of Everyday Experience *Institutional Ethnography As Practice*, in Dorothy E Smith. *Institutional Ethnography as Practice*. (The Rowman & Littlefield Publishing Group, 2006.) at 109.

⁶⁰⁰ Spandler & Mckeown *Supra* note 211.

As a final example, in a recent paper, Reaume (a historian himself) addresses criticisms from other historians who contend that real historians of psychiatry have different objectives than “Mad activists” and characterize Mad Studies as an “imagined space.”⁶⁰¹ Reaume underscores the persistent resistance encountered when service users offer historical accounts divergent from the dominant hegemonic psychiatric narrative. He goes on to challenge historians who assert that the efforts of Mad activists to preserve and interpret history are motivated by an “anti-psychiatry” agenda, and argue that symbols from the Holocaust, World War I, and American slavery are being reinterpreted to further the political objectives of service user groups.⁶⁰²

7.3 Final Reflections

A significant implication of my research is that service users need to clearly reignite and continue collective discussions on the need to preserve a fight for collective community building, revisit the need for arm’s length independent advocacy, and shift away from this era that assumes there is democratic relationship with medical experts, intuitional research priorities and this is somehow ameliorated through promises of individual civic patienthood by virtue of giving feedback in focus groups, committee or advisories which the *ECFAA*⁶⁰³ and PDoVs promote amidst the backdrop of an ever expanding era of disability necropolitics.⁶⁰⁴ Yet, even in these times of austerity, service users continue to find ways to resist and subvert these conditions

⁶⁰¹ Geoffrey Reaume, “Historical Memory, Anti-psychiatry, and Mad People’s History” in Elisabeth Punzi and Linda Steele eds. *Sites of Conscience: Place, Memory, and the Project of Deinstitutionalization* (Vancouver: University of British Columbia Press, 2024) at 29.

⁶⁰² *Ibid*

⁶⁰³ *Excellent Care for All Act, Supra* note 1.

⁶⁰⁴ Achille Mbembe introduced the concept of “Necropolitics” in his 2019 book. He argues that sovereignty is fundamentally about controlling life and death, with ultimate power being the ability to determine who lives and who dies. For Mbembe, exercising sovereignty involves defining and managing mortality as an expression of power.

through "hidden activism" driven by practical needs and because the idea of people with disabilities organizing for their rights is still unfamiliar particularly in the West.⁶⁰⁵

From a scholarly perspective, the implications for Mad Studies involve expanding its scope through intersections with other related disciplines. Alternatively, it might address challenges posed by Olúfẹ́mi O. Táíwò in his text *Elite Capture*,⁶⁰⁶ wherein he asks us to examine the ways in which those of us who attach to, or argue our epistemological standpoints, are granted opportunity to occupy positions of power within influential rooms, proceedings, inquests, or courts—perspectives recognized as elite and which garner forms of respect and recognition that starkly contrast with the realities outside these spaces and consequentially intervene in the very practices of giving attention and respect.⁶⁰⁷

To add a final note on the future of legal scholarship: There is a significant opportunity for an alliance between Mad Studies and critical legal theory to explore future legal reform projects. This collaboration could address how change should be implemented, particularly by incorporating the perspectives of service users in meaningful ways that foster mutually constitutive relationships and that build solidarity across movements. This is especially relevant in light of emerging regulatory challenges in healthcare, including issues related to the increasing marginalization of people with disabilities, and the more harmful aspects of AI technology. I am encouraged by the work of some legal students and scholars who are already engaging with Mad Studies, examining the role of identity within mental health law and exploring whether the

⁶⁰⁵ Diana Rose, "A Hidden Activism and its Changing Contemporary Forms: Mental Health Service Users / Survivors Mobilising" (2018) 6:2 *Journal of Social and Political Psychology* at 728

⁶⁰⁶ Olúfẹ́mi O. Táíwò *Elite Capture: How the Powerful Took over Identity Politics (and Everything Else)* (Chicago, Illinois: Haymarket Books, 2022)

⁶⁰⁷ *Ibid* at 79

concept of "mental health" impacts individuals—including those with mental health disabilities, legal scholars, and society at large—in ways that hinder social justice.⁶⁰⁸ Bernheim, highlights the influence of therapeutic jurisprudence theory, which advocates for legal processes that positively impact defendants' mental health and encourage treatment adherence – an issue increasingly worth monitoring.⁶⁰⁹ Additionally, Singh's work, "Rethinking Resilience: Sanism in the Legal Profession," contributes to the field by examining how biases against mental health issues affect the legal field.⁶¹⁰

These considerations lay a promising groundwork for confronting the challenges that lie ahead, particularly through the fusion of theory and praxis and the potential for interdisciplinary collaboration between Mad Studies and Legal Studies. Such collaboration offers the opportunity to craft a more inclusive and equitable model of service use engagement, ensuring that representation is not confined to the privileged few but reflects the diverse realities of the broader community. Though the future is fraught with uncertainty, marked by countless unknowns and forces beyond our control, this unpredictability highlights the delicate interplay between our intentions and their outcomes. Much remains to be done, but I believe we can prepare to engage in this crucial work, seeking reparations for the past to pave the way for a just and equitable future.

⁶⁰⁸ Sheila Wildeman, Agonizing Identity in Mental Health Law and Policy (Part II): A Political Taxonomy of Psychiatric Subjectification, 2016 39-1 *Dalhousie Law Journal* 147, 2016 CanLIIDocs 4133, <<https://canlii.ca/t/sk1j>>, retrieved on 2024-08-18

⁶⁰⁹ Emmanuelle Bernheim, The Triumph of the "Therapeutic" in Quebec Courts: Mental Health, Behavioural Reform and the Decline of Rights, 2022 38 *Windsor Yearbook on Access to Justice* 125, 2022 CanLIIDocs 4255, <<https://canlii.ca/t/7n0xz>>

⁶¹⁰ Palwinder Singh, "Rethinking Resilience: Sanism in the Legal Profession." (2024) 44 *Windsor Rev. Legal & Soc. Issues* at 72.

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APPENDIX A

Hospitals

Hospital	PDoV	Patient Representation
Centre for Addiction and Mental Health (CAMH) (Toronto)	CAMH Patient Bill of Rights	<ul style="list-style-type: none"> ▪ Lived Experience Research Committee ▪ Patient and Family Advisory Committees ▪ The Patient and Family Partners Program ▪ The Empowerment Council: Systemic Advocates in Mental health and Addiction.
Ontario Shores Centre for Mental Health Sciences (Whitby)	Patient Rights and Responsibilities	<ul style="list-style-type: none"> ▪ Patient Advisory and Recovery Committee (PARC).
Parkwood Institute (London)	Our Statement of Patient, Resident and Family Values & Patient Bill of Rights	<ul style="list-style-type: none"> ▪ The Patient Council
Providence Care Hospital (Kingston)	Patient, Client and Resident Declaration of Values	<ul style="list-style-type: none"> ▪ Patient, Client & Family Council
The Royal (Brockville)	Clients Statement of Values	<ul style="list-style-type: none"> ▪ The Client Advisory Council
Southwest Centre for Forensic Mental Health Care (St. Thomas)	Our Statement of Patient, Resident and Family Values & Patient Bill of Rights	<ul style="list-style-type: none"> ▪ The Patient Council
St. Joseph's Health Care Group (Thunder Bay)	Client Rights and Responsibilities	<ul style="list-style-type: none"> ▪ Client and Family Council ▪ Patients' Council ▪ Peer Support/Peer Connections
St. Joseph's Healthcare (Hamilton)	Patient Rights, Responsibilities & Declaration of Values	<ul style="list-style-type: none"> ▪ Patient and Family Advisory Councils ▪ The Peer Support Council
Waypoint Centre for Mental Health Care (Penetanguishene)	Declaration of Recovery Values	<ul style="list-style-type: none"> ▪ The Patient/Client & Family Council