EXPLORING THE EXPERIENCES OF MENTAL HEALTH SERVICE USERS ADVOCATING FOR CHANGES IN MENTAL HEALTHCARE AND POLICY IN ONTARIO

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ABSTRACT

This dissertation focuses on the experiences of mental health service users who have engaged in advocacy work in Ontario to improve mental healthcare and policy. Mad Studies was used as a theoretical lens to center the experiences of mental health service users. Semi-structured interviews through Zoom were conducted with 20 mental health service users who engaged in advocacy work in Ontario to improve mental healthcare and policy to learn about their experiences. They also completed an online demographic survey through Qualtrics.

The dissertation has been divided into seven chapters. The first chapter introduces the Mad Studies lens. The second chapter discusses biomedical dominance in mental healthcare and policy. The third chapter reviews mad resistance, initiatives, and organizing. The fourth chapter outlines the qualitative research design. The fifth chapter discusses the findings from demographic surveys and interviews. The sixth chapter is a discussion of the major themes from the findings, implications for practice and policy, and future directions. The seventh chapter is the conclusion.

Findings reveal that participants were motivated to do advocacy work because of their own lived experience and desire to help others. Their advocacy work focused on education, peer support, increasing collaboration across sectors, and policies. Participants' advocacy work has made impacts through policy change, service creation, organizational change, awareness raising, and helping others. Participants said that promising approaches for improving mental healthcare and policy are increasing funding, increasing supports, greater collaboration in the sector, and including people with lived experience in decision-making. Participants encourage people who want to do advocacy work to practice self-care, have their voice heard, and build relationships.

This dissertation contributes to Mad Studies scholarship by creating knowledge that privileges the experiences and wisdom of people who have used mental health services. It also challenges biomedical narratives and outlines promising approaches for improving mental healthcare and policy in Ontario.

DEDICATION

I dedicate this dissertation to my father who always believed in me and encouraged me to pursue my PhD. May he rest in peace.

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I want to thank the research participants who kindly shared their stories and made this dissertation possible. I would like to acknowledge my dissertation committee, faculty, and staff for their guidance throughout my PhD. I appreciate my work colleagues for accommodating me while I completed this work. I am eternally grateful to my family and friends who spent countless hours supporting me through this journey.

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CHAPTER 1: INTRODUCTION

This dissertation focuses on the experiences of mental health service users who have engaged in advocacy work in Ontario to improve mental healthcare and policy. There are tensions surrounding the correct use of terminology when describing individuals who have experienced mental distress or who have been labelled as having a mental illness (Burstow, 2013)[1]. In order to respect the many ways in which people experiencing mental distress identify, the more neutral and descriptive term mental health service user will be used throughout the dissertation. Reflecting on my own evolving understanding of mental healthcare systems, I chose to adopt a Mad Studies lens. I did this in order to center the voices and knowledge of people with lived experience of mental distress while critically examining dominant psychiatric and societal narratives. However, participants did not hold uniform perspectives and not all participants identified as mad or explicitly challenged dominant understandings of mental illness and mental healthcare. This led to some tensions between the Mad Studies lens I have adopted and how some participants described mental health in ways that reinforced biomedical dominance. Including diverse perspectives strengthens the analysis by reflecting the complexity of lived experience and demonstrating the varied ways in which people who experience mental distress understand, navigate, and engage with the mental healthcare system and advocacy.

Mental health service users have knowledge that is subjugated because it is considered inferior to other types of knowledge, even though it should be considered superior because it is difficult to fully understand the experience of mental distress unless you have lived through it yourself (Boschma et al., 2014; Lancaster et al., 2017). Mental health service users have

[1] Individuals experiencing mental distress self-identify in diverse ways. Individuals who feel they have been harmed by biomedical treatment may prefer to identify as a survivor, individuals who feel neutral or that they have benefited from biomedical treatment may prefer to identify as consumers, and individuals who resist psychiatry and pathologizing their mental distress may prefer to use the term mad. Individuals have their own preferences based on their beliefs and personal experiences. Organizations also refer to individuals experiencing mental distress in diverse ways such as consumer, service user, client, patient etc. depending on where they are situated in the mental healthcare system (Burstow, 2013).

important knowledge to share since they are resourceful and are able to bring their educational, intellectual, artistic, and practical abilities from their lives to politically engage and create networks that lead to improved mental healthcare services (Boschma et al., 2014; Morrow, 2017). When decision makers listen to the voices of mental health service users, it allows mental health service users to influence mental healthcare and policy in ways that reflect their diverse experiences and are beneficial to them.

Mad Studies will serve as a theoretical lens to center the experiences of mental health service users in generating knowledge about resisting the biomedical model of mental illness and advocating for improvements to the mental healthcare system. A Mad Studies lens can be used to highlight how knowledge about madness has been framed medically and scientifically in ways that can cause harm to people experiencing mental distress (Pilling, 2025). I use the Mad Studies lens in this way in chapters 2 and 3 to highlight the dominance of the biomedical model of mental illness in mental healthcare and policy as well as some of the criticisms of this model. A Mad Studies lens can also be used to create knowledge that privileges the experiences and wisdom of people experiencing mental distress (Pilling, 2025). I use the Mad Studies lens in this way in chapters 4 and 5 which outline the methodology used to create knowledge from the experiences of mental health service users and the findings of the research study. This dissertation will add to the field of mad scholarship by creating knowledge about how to improve mental healthcare and policy through advocacy from the perspective of people with lived experience of mental distress. This builds on the current literature that highlights the resistance and initiatives that have been spearheaded by people who identify as mad and their allies.

Mad Studies has its origins in the activism of people who reclaimed the pejorative term mad as a positive disability identity (Beresford, 2020; Redikopp, 2021). Mad Studies focus on

the experiences, perspectives, and knowledge of mad people to question psychiatric powers, address epistemic injustice, and bring about positive social change (Gorman & Le Francois, 2018; Johnston, 2020; Reaume, 2022; Redikopp, 2021). Mad Studies challenges the assumption that mental distress is caused by individual pathology which requires biomedical treatment and invites us to consider a broader range of emotions and behaviours as rational responses to challenging circumstances caused by social, economic, and environmental factors (Gorman & LeFrancois, 2018; Morrow, 2017; Redikopp, 2021).

The shift from institutionalization to deinstitutionalization in Ontario laid the groundwork for the emergence of the mad movement, as individuals began to resist the systemic harms of asylum-based care and its community-based successors (Morrow et al., 2008). While deinstitutionalization was intended to promote community integration, it often resulted in transinstitutionalization—where former patients moved from hospitals to prisons, shelters, or unsupported housing due to a lack of adequate community services (Fabris, 2011). This failure sparked a new wave of activism led by those with lived experience who rejected the pathologizing frameworks of psychiatry and demanded autonomy, rights, and structural change (Costa et al., 2012).

Historically, mental health service users have been largely excluded from influencing mental health policy and practice, with decision-making dominated by psychiatric professionals and institutions rooted in biomedical authority (Costa et al., 2012). However, beginning in the 1970s, user-led movements began to challenge this exclusion. The Mental Patients Association was started in Vancouver in the 1970s and it was the first advocacy and user led group in Canada (Beckman & Davies, 2013). The Mental Patients Association inverted hierarchies by putting former patients and allies in charge of peer led community support (Boschma et al., 2014). In

Ontario, the emergence of organizations like On Our Own, founded in 1977, marked a pivotal moment in mad activism and the demand for rights-based approaches to mental health (Reaume, 2002). These early forms of resistance rejected coercive psychiatric practices and sought to reframe mental illness through the lens of social justice and human rights (Reaume, 2002). These movements were instrumental in creating space for the voices of psychiatric survivors within broader left-wing political struggles, foregrounding the need for lived experience in shaping mental health reform (Reaume, 2002).

Mental health service users influence policy and practice through formal consultation roles, advisory bodies, and the growing field of Mad Studies (Starkman, 2013). The Government of Ontario (2011) incorporated service user perspectives into mental health planning processes, such as the development of the *Open Mind, Healthy Minds: Ontario's Comprehensive Mental Health and Addictions Strategy* which emphasized the importance of person-centered care and community-based support. The most recent Ontario mental health and addictions plan called the *Roadmap to Wellness* (2020) was developed after consulting with hundreds of individuals including people with lived experience. Nevertheless, user involvement often remains tokenistic, with limited influence on structural change (Costa et al., 2012). Academics and activists alike argue for a shift from consultation to co-production, where service users are equal partners in designing and evaluating mental health systems (Costa et al., 2012). Ontario's Psychiatric Survivor Archives of Toronto[2] and survivor-led initiatives like Sound Times[3] and the

[2] https://medhumanities.ca/lam/psychiatric-survivor-archives-of-toronto-toronto-ontario-canada/
[3] https://www.reconnect.on.ca/soundtimes

Empowerment Council[4] exemplify ongoing efforts to institutionalize user-led knowledge and challenge dominant paradigms in mental healthcare.

This dissertation research will help address equity issues by privileging the voices of mental health service users. Understanding the experiences of mental health service users challenges dominant perspectives about mental healthcare and policy (Johnston, 2020). This research could lead to greater knowledge about promising approaches to improve mental healthcare and policy that are not dominated by the biomedical model of mental illness. This research will add to the literature by further exploring the experiences of mental health service users who advocate for changes in mental healthcare and policy in Ontario. Understanding the advocacy experiences of mental health service users might challenge biomedical dominance, provide knowledge on how to include the voices of mental health service users in decision-making related to mental healthcare and policy, and help improve mental healthcare and policy in ways that benefit mental health service users.

In keeping with a Mad Studies theoretical lens, I have employed methods that are best suited to get at the rich and varied experiences of mental health service users who are trying to influence change in mental healthcare and policy in Ontario. To this end, I conducted semi-structured interviews through Zoom with 20 mental health service users who have engaged in advocacy work in Ontario to improve mental healthcare and policy within the context of the current mental healthcare system and their communities. I also asked the 20 mental health service users to complete an online demographic survey through Qualtrics which helped highlight correlations between social location and advocacy experiences.

[4] https://www.camh.ca/en/patients-and-families/information-for-patients/your rights/empowerment-council

The dissertation has been divided into seven chapters. The first chapter introduced the Mad Studies lens that will be used to explore the advocacy experiences of mental health service users, and it emphasizes the importance of listening to the voices of mental health service users. The second chapter discusses biomedical dominance in mental healthcare and policy and outlines the critiques of the biomedical model of mental illness. The third chapter reviews how mad resistance, initiatives, and organizing have improved mental healthcare and policy and challenged biomedical dominance in mental healthcare. The fourth chapter outlines the qualitative research design and provides details about the study population and methods. The fifth chapter discusses the findings from the demographic surveys and interviews which include participants' advocacy work, impact, challenges, and recommendations. The sixth chapter is a discussion of the major themes from the findings, implications for practice and policy, and future directions. The seventh chapter is the conclusion which discusses the importance of this research study.

CHAPTER 2: BIOMEDICAL DOMINANCE IN MENTAL HEALTHCARE AND POLICY

2.1 Introduction

This chapter will argue that the biomedical model of mental illness dominates mental healthcare and policy in Canada and negatively affects the health and well-being of individuals. This chapter will start with a background on mental illness prevalence in Canada and the mental healthcare system. The first section will discuss the history of Canadian mental healthcare policy and how this history has been shaped by Medicare, funding, and neoliberalism. The second section will discuss the history of Ontario's mental health policy and how this history has been shaped by institutionalization, deinstitutionalization, the Mental Health Act, and policy reforms. The third section will outline the biomedical model of mental illness and how it has been promoted by the pharmaceutical industry. Critiques of the biomedical model of mental illness will be highlighted in the final section.

2.2 Background

Throughout the chapter the terms mental illness and mental distress will be used. The term mental illness will be used because it is the predominant way of describing people with mental distress within the biomedical model and it is the term commonly used within the literature to describe an individual with a diagnosis of mental illness. The term mental distress will be used to question biomedical dominance and acknowledge the role that social, political, and environmental factors play in mental health challenges. In subsequent chapters I will be engaging with literature that prioritizes the lived experience of mental health service users so I will use language such as consumer, survivor, and mad which does not pathologize the mental health service user and is commonly used in Canada.

Mental illnesses are one of the most prevalent, chronic, and disabling illnesses (Shim et al., 2014). The World Health Organization defines mental illness as a clinically significant

disturbance in an individual's cognition, emotional regulation, or behaviour that usually causes distress or impairment in a person's personal, social, educational, occupational, or other important areas of their lives (World Health Organization, 2022). Mental illness can emerge anytime throughout the lifetime and exists on a continuum where individuals can experience different degrees of distress that lead to different outcomes (Briante et al., 2011; World Health Organization, 2022). Individuals with mental illness can experience episodes of well-being and distress at different stages in their lives.

Mood, anxiety, and substance use disorders are the most common mental illnesses that affect Canadians (Stephenson, 2023). The prevalence of these common mental illnesses has increased significantly over the last ten years with more than five million people in Canada meeting the diagnostic criteria for a mood, anxiety, or substance use disorder in 2022 (Stephenson, 2023). In Ontario, over one million people a year experience mental health and addiction challenges (Government of Ontario, 2020). These statistics are based largely on biomedical Diagnostic and Statistical Manual (DSM) criteria which I will discuss later in this chapter. These statistics likely do not accurately capture the number of people experiencing mental distress since not everyone experiencing mental distress seeks out biomedical treatment or receives a diagnosis. Mental illness impacts individuals, their families, communities, and the healthcare system (Briante et al., 2011). There are direct, indirect, and intangible costs associated with mental illness. Direct costs of mental illness are associated with the use of healthcare and social services (Hewlett & Moran, 2014). The direct cost of mental illness is estimated to be $42.3 billion in Canada (Briante et al., 2011). Indirect costs of mental illness include lost productivity, unemployment, lost skills in the labour force, and disability payments (Hewlett &Moran, 2014). The indirect cost of mental illness is estimated to be $6.3 billion in Canada

(Briante et al., 2011). Intangible costs are related to reduced well-being and other forms of suffering (Hewlett & Moran, 2014).

2.3 History of Mental Health Policy in Canada

It is necessary to understand the historical and current policy landscape to better understand the context in which advocates are working. The federal government is responsible for health promotion, disease prevention, disease surveillance, health research, human rights, disability and employment benefits which have indirect implications for mental health services (Kirby, 2004). With funding from Health Canada, the Mental Health Commission of Canada (MHCC) creates and shares tools to support mental health and helps governments and organizations implement effective policies (Mental Health Commission of Canada, 2025). The MHCC has developed suicide prevention initiatives, guidelines for the workplace, best practices for e-mental health, reduced stigma, and emphasizes the importance of listening to the voices of people with lived experience (Mental Health Commission of Canada, 2025).

The federal government can use legal and financial levers to affect mental healthcare (Kirby, 2004). Legal levers include Charter of Rights and Freedoms, Criminal Code, Controlled Drugs and Substances Act, and Broadcasting Act (Kirby, 2004). The Charter of Rights and Freedoms guarantees certain legal rights to individuals who experience mental distress such as the right to life, liberty, security, and the right not to be subject to cruel and unusual punishment (Kirby, 2004). This legal lever is used to ensure that the rights of individuals who experience mental distress are protected in the mental healthcare system. An example of using this legal lever can be seen in the 2014 PS vs Ontario case[5]. In this case, the Ontario Court of Appeals found that Ontario mental health law breached the charter rights of PS because he was permitted

[5] https://www.canlii.org/en/on/onca/doc/2014/2014onca900/2014onca900.html

to be involuntarily detained at a mental health institution indefinitely without being able to challenge the conditions of his treatment (Lipinski, 2015). This decision advanced civil rights for individuals with mental illnesses by recognizing that recovery is an important part of mental health law and thus limited involuntary detentions to six months (Lipinski, 2015).

The Criminal Code outlines when a person is not criminally responsible for an offence due to a mental illness (Kirby, 2004). This legal lever is used to protect individuals who are not criminally responsible for an offence due to a mental illness from certain sentences and punishments. The Controlled Drugs and Substances Act regulates the sale of psychoactive substances (Kirby, 2004). This legal lever is used to protect the public from harmful psychoactive substances. The Broadcasting Act regulates advertising of medications and substances such as alcohol (Kirby, 2004). This legal lever is used to protect the public from harmful advertising practices.

2.3.1 Medicare

Canadian mental health policy has been shaped by Medicare. Medicare is a Canadian national health insurance program which covers the cost of basic medical and hospital services for Canadians (Goering et al., 2000). The majority of primary mental healthcare is delivered by general practitioners and psychiatrists because other healthcare professionals are not covered under Medicare (Goering et al., 2000). Healthcare professionals such a psychologists were excluded from the fee for service Medicare system because governments wanted to limit spending on new services and healthcare professionals (Romanow & Marchildon, 2003). Medicare covers physician and hospital services instead of community care (Mulvale et al., 2020).

2.3.2 Funding Arrangements

Canadian mental health policy has also been shaped by funding arrangements between the federal and provincial governments. The federal government offered provincial governments cost-sharing arrangements to fund psychiatric units in general hospitals (Kirby, 2004). General hospitals were not eligible for federal funding if they assigned more than 10% of their beds to psychiatric care (Hartford et al., 2003). Provincial governments argued that psychiatric hospitals should be included in federal cost sharing, but Ottawa disagreed because psychiatric hospitals received some funding through the mental health grant which lasted several years (Wiktorowicz et al., 2020). The federal government introduced the annual $7,000,000 mental health grant in 1948 to address urgent national priorities including the mental health needs of returning soldiers (Bartram & Lurie, 2017; Wiktorowicz et al., 2020). Mental illnesses were thought to be incurable, so mental healthcare was excluded from the definition of health services except for some emergency services (Wiktorowicz et al., 2020). Institutional and community based mental healthcare was excluded from cost sharing arrangements between the provincial and federal government (Wiktorowicz et al., 2020). Federal transfers were reduced in the 1990s, and healthcare needs were growing which made it difficult for provinces to provide proper mental healthcare (Wiktorowicz et al., 2020). Due to these funding arrangements, emergency mental health services provided through hospitals were publicly funded while most other forms of mental healthcare were excluded from public funding.

2.3.3 Neoliberalism

Neoliberalism has shaped Canada and Ontario's mental health policy in significant ways. Neoliberalism rose with capitalism in the 18th century and started as a set of fiscal policies in the 1970s as a response to the economic downturn (Raphael et al., 2020; Sugarman, 2015).

Neoliberalism aims to decrease government intervention, often leading to reductions in government services and the transfer of risks to individuals (Galvin, 2002; Sugarman, 2015). Neoliberalism emphasizes individual responsibility and economic independence instead of collective citizen rights, equity, and citizenship (Cosgrove & Karter, 2018; Morrow, 2013). After the rise of neoliberalism, the government changed public policies and reduced public spending in these areas which transferred responsibility to individuals for sickness, poverty, unemployment, and homelessness (Galvin, 2002).

Neoliberal policies cut spending on social services and individualize health problems (Morrow, 2013). Individuals are expected to invest more time and energy into becoming and remaining healthy since they are viewed as consumers who can buy products and services to improve their health and prevent illnesses (Galvin, 2002; Rosenthal, 1998). However, the populations most at risk for health problems are the ones who have the longest working hours, highest rates of unemployment, and declining income which means they have the fewest resources to invest in health (Rosenthal, 1998). Doctors are expected to educate the public with the underlying assumption that people can be healthy if they make the right choices (Rosenthal, 1998). However, research does not support the belief that individuals can be healthy if they alter their behaviour because their social conditions such as housing, working conditions, and income create the conditions for how healthy they are (Rosenthal, 1998). For instance, an individual wants to live a healthier lifestyle, but they work long hours at a low-paying job and have little time, money, or access to fresh groceries. Even though they want to change their behaviours, their working conditions, income, and living environment make it difficult for them to do so which demonstrates that health is shaped by social conditions rather than just personal choices.

Psychiatry aligns with neoliberal ideology because it focuses on the individual instead of social context. Biomedicalism and neoliberalism enhance and support one another (Morrow, 2013). The biomedical model assumes that mental health problems exist in the individual so mental health treatment should focus on the individual (Esposito & Perez, 2014). Medications are used to modify individual behaviour so that individuals can be more competitive in the market (Esposito & Perez, 2014). However, neoliberal policies and medications have not resulted in people being happier, saner, less anxious, or less distressed but the opposite trends can be seen instead (Esposito & Perez, 2014). This demonstrates that treating mental distress with medications only has not been effective and that neoliberal policies have negatively affected mental health (Esposito & Perez, 2014).

2.4 History of Mental Health Policy in Ontario

This section outlines how the history of Ontario mental health policy has been shaped by institutionalization, deinstitutionalization, the mental health act, and policy reforms from the 1800s until now. Provinces and territories are responsible for the organization, governance, funding, and delivery of mental health services (Kirby, 2004). Provinces are also responsible for delivering healthcare, housing, and social services (Goering et al., 2000). Provinces and territories are responsible for creating mental health legislation which governs psychiatric treatment for individuals with mental illness (Kirby, 2004). Mental healthcare in Ontario is decentralized and regionalized (Morrow, 2013).

2.4.1 Institutionalization

Institutionalization has shaped mental health policy in Ontario and Canada. Before the 1800s, people with mental distress were in jail, cared for by their family, or by religious bodies (Centre for Addiction and Mental Health, 2025; Kirby, 2004). Families moved from rural to

urban environments during industrialization where they no longer had the means to care for family members with mental distress (Fakhoury & Priebe, 2007). Legislation was passed in Ontario in 1839 that provided funding for a permanent lunatic asylum, required government supervision of the asylum construction, and a board of directors to establish rules, regulations, and appoint employees for the asylum (Moran, 2000). Family members with mental distress were sent to asylums where they would receive basic care and accommodation (Fakhoury & Priebe, 2007). People with mental distress were thought to be incurable so their treatment was custodial and many people with mental distress would spend the rest of their lives in asylums once they were admitted there (Kirby, 2004). People admitted to asylums were routinely put to work, which was a practice that was justified as therapeutic because it provided them with meaningful activity and it was economical because unpaid labor reduced institutional costs (McKay, 2016). However, there were patients who resisted and refused to work while others argued that they should be receiving compensation for their work (Reaume, 2009). After 1960 a small amount of money was paid to patients who worked in asylums, but the amount was well below the poverty line (Reaume, 2004).

Asylums were geographically isolated from the public which led to increased stigma, limited family and public advocacy for reform, and policy decisions were made by psychiatrists, superintendents, and a small number of government officials (Simmons, 1990). Asylums became overcrowded after World War II (Kirby, 2004). Increases in admissions to asylums led to poor living conditions, lack of hygiene, overcrowding, and ill treatment of individuals with mental distress (Fakhoury & Priebe, 2007). Seclusion, chemical, and physical restraints were used on individuals with mental distress when they were in asylums and these practices are still common today (Kirby, 2004). Individuals with mental distress were stripped of their identity in asylums

(Krupinski, 1995). They were not treated and spent their days feeling aimless and doing non-stimulating recreational activities (Krupinski, 1995). Long term institutionalization had negative effects on individuals with mental distress including indifference, apathy, passive obedience, self-neglect, aggressive behavior, loss of social abilities, increased dependence, isolation, and chronic physical illnesses (Kirby, 2004). This led to mental health reforms that included closing asylums and moving individuals with mental distress back into the community where they could receive community mental healthcare services (Fakhoury & Priebe, 2007). This shift to community mental healthcare services is known as deinstitutionalization (Fakhoury & Priebe, 2007).

2.4.2 Deinstitutionalization

Deinstitutionalization has been taking place in Canada from the 1950s up until today but its form has changed over time (Shera et al., 2002). Deinstitutionalization was driven by developments in drug treatment, psychosocial rehabilitation, understanding of the negative impacts of institutionalization, concerns about the civil rights of individuals with mental distress, and cost considerations (Morrow et al., 2008). There were three processes of deinstitutionalization (Sealy & Whitehead, 2004). The first process was shifting away from psychiatric hospitals, the second process involved increasing mental health beds in general hospitals, and the third process was to increase community-based mental healthcare for individuals experiencing mental distress (Sealy & Whitehead, 2004).

Initial deinstitutionalization policies assumed that mentally ill individuals would have the resources, housing, jobs, support, and supervision they needed in the community (Krupinski, 1995). However, in the early days patients were discharged from institutions into the community without proper support, preparation, and care (Fakhoury & Priebe, 2007). This resulted in

mentally ill individuals not receiving the treatment they needed (Fakhoury & Priebe, 2007). Since there was limited community support available, individuals with mental distress would deteriorate which led to hospital readmissions and poor mental health outcomes (Wiktorowicz, 2005). Due to lack of services and support in the community, individuals with mental distress had a high frequency of relapses, homelessness, and incarceration (Kirby, 2004).

Families were sometimes unable to care for family members with mental distress because often both parents were working (Fakhoury & Priebe, 2007). Individuals with mental distress who were living with family put a burden on their family which could lead to family breakdown and negatively affect the mental health of other family members (Krupinski, 1995). Many individuals with mental distress who were discharged from institutions did not have family to rely on and lived on the streets without help or protection (Krupinski, 1995). Many individuals ended up in shelters where living conditions were worse than psychiatric institutions because they were robbed and physically assaulted (Krupinski, 1995). A majority of individuals with mental distress are not a part of the workforce, have limited social connections, and live in sheltered environments (Fakhoury & Priebe, 2007).

2.4.3 Mental Health Act

Each province and territory has its own Mental Health Act which outlines slightly different protocols for when individuals can be involuntarily committed to psychiatric institutions (Canadian Mental Health Association, 2021). The Mental Health Act was developed in part as a response to deinstitutionalization to provide a legal framework to allow individuals to be admitted to psychiatric care when necessary. According to the Ontario Mental Health Act, a person can be taken to a psychiatric facility to be examined by a physician if they are acting disorderly and threatening or attempting to cause serious bodily harm to themselves or others or

lack the competence to care for themselves (Mental Health Act, 1990). After the person is taken into custody by the psychiatric facility, they can be involuntarily committed (Frankenburg, 1982; Mental Health Act, 1990). A physician can involuntarily commit a person if that person had previously been treated for a mental disorder that, if left untreated, would cause serious bodily harm to themselves or others, has shown signs of improvement after treatment, is suffering from the same mental disorder, is likely to cause serious bodily harm to themselves or others, is incapable of consenting to psychiatric treatment, and is not suitable for admission as a voluntary patient (Mental Health Act, 1990).

The Mental Health Act allows mental healthcare professionals to control individuals experiencing mental distress through physical and chemical restraints, medications, surveillance, involuntary commitment and treatment, punishment, and reward systems (Johnston et al., 2023). Individuals who are considered a risk to themselves or others can be involuntarily committed to a hospital where they are not allowed to leave and can be forced into treatment against their will (Harrison et al., 2015). Many mad people experience distress and discomfort when coercion is used in the form of involuntary commitment, involuntary treatment, threats, physical or chemical restraints, and seclusion (Harrison et al., 2015). A tension exists where some people view the Mental Health Act as a tool that can help individuals get access to care while other people view it as a tool that is used to control individuals. In Ontario, an involuntary treatment order can be changed to a community treatment order (Weller et al., 2019). A community treatment order requires an individual to accept mental health treatment since it is a legal order under the Mental Health Act and it is used to ensure individuals are following their treatment plan once they are discharged from the hospital (Weller et al., 2019). Compulsory treatment is often associated with feelings of powerlessness and a lack of control even if mad people recognize that community

treatment orders can improve the quality of care they receive and give them more access to care (Weller et al., 2019). Many mad people recognize their need for support but feel that their rights are taken away, they are not being heard, and their views on treatment options are being ignored when they are on a community treatment order (Weller et al., 2019).

2.4.4 Mental Health Policy Reforms

Ontario began formalizing community mental health policy from 1980s to 2000s. *Towards a Blueprint for Change: A Mental Health and Policy and Program Perspective* (1983) report provided support for a continuum of care in service delivery so that people with mental illnesses could receive the support they needed in their communities. *Building Community Support for People: A Plan for Mental Health in Ontario* (1988) report argued that mental health care should be delivered close to home in a way that is person-centered, equitable, culturally sensitive, and inclusive. *Putting People First: The Reform of Mental Health Services in Ontario* (1993) recommended the integration of community and institutional services with a reallocation of funding from institutions to community services. *Making It Happen: Implementation Plan for Mental Health Reform* (1999) aimed to shift care from institutions to community-based services through a tiered model of support that ranged from prevention, supportive housing, case management, and residential treatment. It emphasized better coordination across providers, prioritizing people with serious mental illnesses, and introduced mobile crisis teams. Despite these reports, there was not enough community-based care, affordable housing, and financial support for individuals who were previously institutionalized (Hartford, 2003).

Mental health policy in Ontario from 2000s to 2020s emphasized integration with primary health care and the broader health care system. Family Health Teams were designed to integrate mental health into primary care by including social workers, psychologists, and

psychiatrists in the same settings as physicians (Mulvale et al., 2009). Fourteen Local Health Integration Networks were created in 2006 in Ontario to plan and coordinate services regionally and were transitioned into Ontario Health Teams in 2019 (Bhasin & Williams, 2007; Government of Ontario, 2019). *The Open Minds, Healthy Minds: Ontario's Comprehensive Mental Health and Addictions Strategy* (2011) also outlined a plan to support the mental health of Ontarians by providing mental health support and integrated services. Unfortunately, there was still not enough continuity of care in mental healthcare and patients found it difficult to navigate the healthcare system (Wiktorowicz et al, 2020).

In the 2020s and beyond, Ontario continues to struggle with fragmentation, underfunding, and a growing demand for mental health services that is exacerbated by COVID-19 (Hao et al., 2024). *The Roadmap to Wellness* (2020) is the most recent provincial mental health and addictions plan. In this plan, the Ministry of Health has committed to providing Ontarians "access to high-quality, easily accessible mental health and addictions support through their lifetime, where and when they need it" by investing $3.8 billion over 10 years to implement a comprehensive mental health and addictions system. Consultations with hundreds of mental health and addictions organizations, frontline staff, hospitals, advocates, experts, and people with lived experience revealed that there needs to be more investment in community-based care and that the system is too fragmented.

2.5 Promotion of the Biomedical Model of Mental Illness

Mental health theory and practice in Canada is most influenced by the biomedical model of mental illness which focuses on individual pathology (Larsson, 2013). Complex relationships between biomedicine, science, and society co-produce psychiatry and lead to the dominance of the biomedical model of mental illness (Pickersgill, 2012). Psychiatry operates through the

Diagnostic and Statistical Manual which emphasizes biomedical treatment such as medications in order to modify individual biology and behaviour (Esposito & Perez, 2014; Morrow, 2017; Pickersgill, 2012). Mental healthcare professionals such as psychiatrists are taught about the social determinants of mental health but they tend to focus on biomedical treatment since those treatments are publicly funded. There are publicly funded treatments that are not biomedical such as therapy, but it tends to be for a limited number of sessions. Another factor that contributes to the dominance of the biomedical of mental illness is the ideological assumption that mental illness is caused by brain diseases that are biologically based (Deacon, 2013). It is assumed that the cause of health problems lies within the individual and is a result of their biology and choices (Raphael et al., 2008). Mental health can be affected by biology and choices which means biomedical treatment can be useful to a certain extent. However, there are other factors that need to be considered when addressing mental health and alternative holistic treatment options should be provided.

The Diagnostic and Statistical Manual (DSM) was introduced by the American Psychiatric Association in 1952 to create a consistent way of diagnosing mental disorders (Kress et al., 2014). The manual contained narrative and psychodynamic descriptions of mental disorders (Kress et al., 2014). An emphasis on diagnosis rather than understanding the story of the individual with mental distress started with DSM III in 1980 (Double, 2003). DSM III introduced a scientific and biologically based psychiatry and a multiaxial system (Aho, 2008; Kress et al., 2014). Anxiety disorders, mood disorders, and dissociative disorders were considered Axis I disorders because they could be identified by observable behaviours (Aho, 2008). Personality disorders were considered Axis II disorders and were thought to be problems of character and problems of living that would take a long time to treat (Aho, 2008). Managed

care organizations decided not to reimburse healthcare professionals for Axis II disorders which resulted in Axis I disorders being considered true illnesses that could be objectively identified, treated, and evaluated (Aho, 2008).

DSM I and II recognized the importance of social relationships and understood individuals in relation to their social interactions (Aho, 2008). Starting with the DSM III, observable behaviours were focused on in order to remain unbiased and neutral (Aho, 2008). Mental illness was defined the same way as physical illness where the individual's biology is the cause of illness (Aho, 2008). Mental distress is considered a real mental illness only in circumstances where mental distress is not due to social context (Aho, 2008). For instance, if an individual experiences the symptoms of depression temporarily because of the death of a family member, the individual is not considered to have a mental disorder. If an individual experiences the symptoms of depression persistently and they are not caused by social context, the individual is considered to have the mental disorder. The DSM III and its successive editions helped construct the biomedical model of mental illness (Aho, 2008).

The process of creating DSM IV, which was introduced in 1995, was criticized as biased, arbitrary, and lacking empirical evidence (Caplan, 1991). The creation of certain disorders was criticized as pathologizing feminine behaviour and sexual orientations that are not heterosexual (Caplan, 1991). The DSM V was introduced in 2013 and it eliminated the multiaxial system for mental disorders that started with DSM III (Kress et al., 2014). There were five Axes introduced in DSM III. Axis I and II have been discussed above. Axis III focused on medical or neurological problems (Kress et al., 2014). Axis IV focused on nine categories of psychosocial or environmental stressors which included primary support group, social environment, education, occupation, housing, economic, access to health care, legal system/crime, and other (Kress et al.,

2014). Information in Axis IV was supposed to be used to supplement diagnosis on Axis I and Axis II. Insurance companies did not provide coverage for counselling for an Axis IV diagnosis only (Kress et al., 2014). Axis V focused on a global assessment of functioning rating which referred to the level of distress or impairment an individual experienced (Kress et al., 2014). The American Psychiatric Association eliminated the multiaxial system in 2013 because they believed it was not required to make a diagnosis (Kress et al., 2014). The American Psychiatric Association defined mental disorder as a dysfunction in the psychological, biological, or developmental processing underlying mental functioning which suggests that mental disorders are result of individual biology (Kress et al., 2014).

The pharmaceutical industry promotes the biomedical model of mental illness through the government by influencing mental health policy, legislation, research, education, and practice due to its power and resources (Whitaker, 2007). The pharmaceutical industry promotes the biomedical model of mental illness by redefining health problems so that they have a pharmaceutical solution (Williams et al., 2011). The pharmaceutical industry markets mental illnesses and medications by turning ordinary problems into medical problems, framing mild symptoms as serious, framing risks as illnesses, and exaggerating prevalence estimates (Williams et al., 2011). For instance, children are increasingly being diagnosed with mental illnesses and prescribed medications to treat mental illnesses in Canada over the past few decades (Timimi, 2010). There has been a shift in thinking that normal childhood behaviours, such as being boisterous, are symptoms of mental illnesses such as Attention Deficit Hyperactivity Disorder (Timimi, 2010).

In North America, clinical research was publicly funded before the 1980s, but it is now mostly funded by drug and other medical industries that are focused on maximizing profits

(Whitaker, 2007). The pharmaceutical industry primarily sponsors 70% of clinical trials in Canada (Government of Canada, 2021). Academics have received grants from pharmaceutical industries to study their products (Dumont, 1990). The findings are reported in journals and at conferences that the pharmaceutical industry pays for (Dumont, 1990). Medical journals are dependent on pharmaceutical advertising for funding (Whitaker, 2007). Research reports are ghost written so that they promote the medications of specific companies which makes them unreliable (Whitaker, 2007). Pharmaceutical companies sometimes only buy journal advertising if it is accompanied by positive editorials about their products (Washington, 2011). These practices affect Canadians because pharmaceutical companies such as Pfizer are multinational companies with Canadian subsidiaries.

The pharmaceutical industry can also affect regulation by influencing regulatory agencies, lobbying, donations, and other activities including having representatives on task forces which form policies (Lexchin, 2019). Sixty nine percent of the DSM V task force members have ties to the pharmaceutical industry (Cosgrove & Krimsky, 2012). All experts on two DSM-IV panels were funded by the pharmaceutical industry and their products were considered or included in the clinical practice guidelines (Cosgrove et al., 2008). This raises concerns because psychopharmacology is the recommended treatment in clinical practice guidelines (Cosgrove et al., 2008). DSM V panels are responsible for revisions to diagnostic categories and for including new disorders in a diagnostic category (Cosgrove & Krimsky, 2012). The DSM V panels with the greatest number of experts with ties to the pharmaceutical industry are the ones that recommend pharmaceutical treatment for disorders (Cosgrove & Krimsky, 2012). These practices affect Canadians because psychiatrists in Canada use the DSM V to diagnose mental illnesses.

There is concern about the relationship between physicians and the pharmaceutical industry (Washington, 2011). Financial ties between experts and the pharmaceutical industry include honoraria, equity holdings in a pharmaceutical company, principal in a startup company, member of a scientific advisory board of a pharmaceutical company, expert witness for a company in litigation, patent or copyright holder, consultancy, collaborator in a study funded by the pharmaceutical industry, and gifts from pharmaceutical companies (Cosgrove et al., 2008). Even a small gift can influence the prescribing behaviour of physicians (Cosgrove et al., 2008).

The pharmaceutical industry also provides physicians with continuing medical education (Lexchin, 2019). The pharmaceutical industry hires experienced physicians as speakers under the guise of education instead of marketing (Washington, 2011). Pharmaceutical companies spend $2 billion a year on education they provide to healthcare professionals (Washington, 2011). This education familiarizes physicians with brand name products to the exclusion of cheaper, safer, and more effective alternatives (Washington, 2011). Promoting medications to physicians also leads to inappropriate prescribing (Lexchin, 2019).

Pharmaceutical companies have manipulated well-intentioned consumer groups into supporting their biological model of mental illness in return for much needed financial support (Fisher, 2003). The critical edge of consumer groups is compromised through their participation in governance structures and alliances with the pharmaceutical industry (Jones, 2008). The pharmaceutical industry wishes to use patients as a means of deregulation and market expansion (Williams et al., 2011). There is concern that groups are being used by the pharmaceutical industry to indirectly lobby health-care decision makers to secure drug treatments for conditions which may be better served by alternative treatments (Jones, 2008). The pharmaceutical industry

may be using consumer groups to reshape or redefine the groups' concerns to match their own and creating a situation which mutes groups' critique of their actions (Jones, 2008).

Before the 1900s, depression was portrayed as being caused by many things such as life circumstances, emotional attachments, thought patterns, and behaviours (Clarke & Gawley, 2009). Psychoanalytic theories assumed that mental illnesses were caused by unconscious conflicts that originated in childhood and that treatment should focus on talking to therapists to bring awareness to inner thoughts and conflicts (Paris, 2005). Many different treatments were recommended for depression such as therapy, self-help, social connection, and exercise (Clarke & Gawley, 2009). In the 1900s and after the rise of neoliberalism, the media started to portray depression in ways that aligned with the pharmaceutical industry's interests. Psychoanalytic theories became less popular due to poor treatment outcomes, the emergence of neuroscience, and a desire for greater scientific standards (Paris, 2005). Depression was portrayed as resulting from biology, biochemistry, genetics, and other biomedical factors (Clarke & Gawley, 2009). Social causes of mental distress were downplayed, and molecular and genetic risk factors were emphasized (Shim et al., 2014). This occurred even though there were many different theories about depression and there was little evidence within biology about the causes of depression (Clarke & Gawley, 2009). The media claimed that anyone could have depression which expanded markets for the pharmaceutical industry (Clarke & Gawley, 2009). The promoted treatment for depression was medication and therapy which increased profits for the pharmaceutical industry and individualized the causes of mental distress (Clarke & Gawley, 2009).

2.6 Critiques of the Biomedical Model of Mental Illness

The anti-psychiatry and ex-patient movement tarnished psychiatry's reputation and questioned the validity of the biomedical model of mental illness. Psychiatry was viewed as oppressive and used to exert social control over the "unwanted" people in society (Gordon, 2010). Psychiatry was not regarded in high esteem because effective treatments were lacking before the introduction of medications (Kirby, 2004). Psychoanalysis was viewed as vague, prolonged, and expensive treatment that was ineffective and poorly grounded in science (Gordon, 2010). Psychiatry tried to enhance its authority and credibility by promoting a biomedical model of mental illness and medical treatments (Moncrieff et al., 2005). Psychiatry gained scientific respectability and credibility with the discovery of medications and how they worked (Gordon, 2010). The biomedical model of mental illness needs to be defended and promoted by psychiatrists in order to justify psychiatric treatment (Double, 2003). For instance, the idea that depression is caused by abnormal levels of brain chemicals such as serotonin has been used to justify treating depression with antidepressants (Moncrieff et al., 2022). However, there is no convincing evidence that low concentrations of serotonin are associated with depression (Moncrieff et al., 2022). Psychiatry is also vulnerable to the influence of the pharmaceutical industry because there is no biological test for mental illnesses (Moncrieff et al., 2005).

There have been significant criticisms of psychiatry from psychiatrists over the years. Psychiatrists Breggin and Szasz have argued that there is no scientific evidence to prove that mental illnesses are brain disorders and there is significant evidence that medications used to treat mental illnesses such as anti-psychotics and amphetamines have significant side effects (Breggin, 2014; Szasz, 2011). Side effects include brain atrophy, drug dependence, suicidality, tics, apathy, indifference, compulsive behaviours, sexual dysfunction, spasms, and brain damage

(Breggin, 2014). Individuals experiencing mental distress have a reason to be distressed that is not based on biology and they need to be understood so that they can be helped to overcome their challenges (Szasz, 2011). Medications do not address the underlying psychosocial and educational issues that cause individuals to experience mental distress since they only suppress the expression of distress temporarily while adding impairments to the brain (Breggin, 2014). Framing mental distress as mental illness allows psychiatry to violate individual autonomy and exercise social control over individuals who exhibit behaviours that are not considered normal (Szasz, 2011).

The biomedical model of mental illness has been criticized because it pathologizes individuals experiencing mental distress in order to justify coercive, violent, and harmful biomedical treatment (Daley et al., 2019). The biomedical model of mental illness also assumes that knowledge is objective, value free, and can be obtained through scientific methods which ignores, silences, and erases the knowledge and subjective experiences of people experiencing mental distress (Larsson, 2013; Morrow, 2017). This model does not adequately account for the social, political, cultural, and economic contexts that can lead to illness even though how illness is experienced and reported by individuals depends on psychological, social, cultural, economic, environmental, and structural factors (Morrow, 2013; World Health Organization, 2022). In some cases, biological abnormality is present, but the patient is not ill which highlights the fact that biological abnormality alone does not cause disease (Engel, 1977). The patient- physician relationship and researcher biases also influence health outcomes for patients, but this is not considered adequately in the biomedical model (Engel, 1977; Raphael et al., 2008).

The biomedical model of mental illness negatively affects Canadians. The main treatment for mental illnesses according to the biomedical model is medication which can be helpful, but it has side effects which can cause people to become chronically ill and experience new or worsening symptoms (Esposito & Perez, 2014). Side effects can also take years to surface (Whitaker, 2007). Patients are prescribed medications where side effects are downplayed and alternative treatments are ignored (Moncrieff et al., 2005). Even though prescriptions have increased, suicide and other related behaviours have not decreased (Whitaker, 2007). Whitaker (2007) found that many people continue to take medications because they are pressured to comply with their treatment (Whitaker, 2007). They are unaware of the harmful side effects or alternative treatments such as healthy lifestyles, psychotherapy, psychosocial programs, and positive environments (Whitaker, 2007).

For most mental illnesses a range of treatments can be helpful. Psychological services are more cost effective than medications and can effectively treat a wide range of mental health problems (Peachy et al., 2013). Cognitive behavioural therapy strategies have proven to be useful in lifestyle modification, cognitive restructuring, increasing coping skills, and promotion of psychological well-being (Fava, 2009). Psychotherapy allows people to self-manage by healing themselves through psychological means (Fava, 2009). Drugless therapies provided by psychologists are more effective than drug therapies (Romanow & Marchildon, 2003). A barrier to accessing these treatments is having to pay for them (Hewlett & Moran, 2014). Long wait times and inappropriate short-term therapy provided by the public sector means that more patients turn to the private sector for therapy even though they struggle to afford it (Lousada et al., 2015).

Individualistic solutions such as medications prevent people from working together and finding community-based solutions to sadness and social issues (Clarke & Gawley, 2009). Mental distress is associated with oppression, discrimination, inequality, racism, etc. (Clarke & Gawley, 2009). These social inequities are ignored when we focus on medications which could lead to not attempting to make needed political and economic changes (Clarke & Gawley, 2009). Since the biomedical model focuses primarily on medications, it overlooks social support and personal reflection which can increase distress and feelings of isolation (Gordon, 2010).

The biomedical model of mental illness does not take the perspectives of individuals with mental distress into account. The biomedical model of mental illness is aligned with positivist Western science which does not typically accept people's experience as valid knowledge (Acoose et al., 2009). Van veen et al. (2019) who were commenting on the mental health crisis in Vancouver, British Columbia, noticed that people with mental distress were not viewed as legitimate knowledge creators (Van veen et al., 2019). Their voices were silenced and their understanding of their own experiences were doubted (Van veen et al., 2019). Local understandings of mental distress and solutions were not valued since solutions proposed by authoritative figures were privileged over other solutions (Van veen et al., 2019). The desire to build consensus caused civic participation to be nothing more than problem solving and program implementation which eliminated politics, conflict, and discussion about values (Van veen et al., 2019). Consensus can shut down alternative understandings and solutions while issues such as poverty, racism, sexism, and homelessness are ignored (Van veen et al., 2019). This prevents individuals with mental distress from getting the supports they need. It also prevents discussion, problem solving, and change around the social, environmental, and political issues that lead to mental distress.

Western concepts of mental illness cannot be assumed to be valid in non-Western cultures (Summerfield, 2017). Mental health is based on Western concepts that focus on white middle-class people (Czyzewski, 2011). This results in class related misdiagnosis and cultural inappropriateness (Czyzewski, 2011). Some non-Western cultures do not define emotion as internal, biological, unintentional, distinct from cognition, and a characteristic of individuals rather than situations (Summerfield, 2017). Some people do not see depression as a disease (Summerfield & Veale, 2008). Instead, they view it as a situational problem that does not require the intervention of a physician (Summerfield & Veale, 2008). Screening instruments do not assess the context and complexities of individual's lives so they assess normal distress as pathology and inflate prevalence data (Summerfield & Veale, 2008).

Some researchers have found that mental health outcomes are better in the non-industrialized world, especially in populations who do not have access to medications (Timimi, 2010). For instance, individuals diagnosed with schizophrenia from developing countries have better outcomes than similarly diagnosed individuals from developed countries (Padma, 2014). They experience fewer delusions and hallucinations, less disorganized speech, and improved social functioning which could be due to better socio-cultural conditions (Padma, 2014). Despite this fact, the pharmaceutical industry is campaigning for greater recognition of mental illness in the non-industrialized world because this opens up new markets for medications (Timimi, 2010). However, these treatments might be ineffective and can have serious side effects (Timimi, 2010). It also paints alternative perspectives as ignorant even though non-western approaches have worked well for those populations (Timimi, 2010). When we do not engage with alternative perspectives it prevents us from benefitting from those perspectives (Timimi, 2010). Promoting

medications as necessary can erode social ways of coping with problems (Summerfield & Veale, 2008).

Despite the enduring strength of the biomedical model, internationally there has been a shift away from the traditional biomedical model of mental illness towards holistic, rights-based approaches, a transition driven by major institutions like the World Health Organization and the United Nations. The World Health Organization (2025) released new guidelines emphasizing that many countries still rely on outdated institutional models that fall short of international human rights standards. The guidelines strongly advocate for mental health systems anchored in human rights, community-based care, social inclusion, and the meaningful participation of individuals with lived experience. Similarly, the United Nations, through its Office of the High Commissioner for Human Rights and underpinned by instruments like the Convention on the Rights of Persons with Disabilities, has consistently called for the harmonization of national mental health laws and services with human rights frameworks. The 2018 United Nations report *Mental Health and Human Rights: Report of the United Nations High Commissioner for Human Rights* has urged member states to dismantle coercive, pathologizing practices and replace them with community-based, participatory, and rights-affirming care models. Together, these international efforts reflect a paradigmatic reorientation from a disease-centered mindset to one that emphasizes dignity, autonomy, and structural transformation in mental health policy.

The impact of colonial policies that negatively affect the mental health of Indigenous peoples are also ignored in the biomedical model of mental illness. Colonial policies that have negatively impacted the mental health of Indigenous peoples include policies related to residential schools, the Indian Act, forced relocation, children welfare processes, separating children from their families and communities, preventing the transmission of Indigenous identity

and traditions, and undermining the role of women (Allan & Smylie, 2015). The most commonly experienced mental health related issues in Indigenous communities are suicide, alcoholism, and feelings of demoralization (de Leeuw et al., 2010). There is a high incidence of post-traumatic stress disorder in residential school survivors and a high prevalence of comorbid mental illnesses (Czyzewski, 2011). High suicide rates for Indigenous peoples are tied to trauma, family and community abuse, violence, and a lack of access to healthcare and social services (Hillier et al., 2021). Chronic pain is closely tied to trauma and other psychological issues (Nelson et al., 2016).

Indigenous peoples are seen as a homogenous group that have high rates of mental health problems which require individualized biomedical and psychiatric treatment (McKenzie et al., 2016). These interventions ignore the social, historical, and colonial conditions that have led to poor mental health outcomes in Indigenous Peoples (McKenzie et al., 2016). Stories about Indigenous Peoples mental health in mainstream Canadian society tend not be produced by Indigenous peoples (Allan & Smylie, 2015). This leads to stories of Indigenous mental health which often include racist stereotypes and images (Allan & Smylie, 2015). These stories promote the idea that Indigenous peoples' negative mental health outcomes are a result of their physiological and biomedical problems instead of colonial policies that have negatively impacted Indigenous communities (Allan & Smylie, 2015). Mental health services that have not been designed by Indigenous peoples are under-used by them because they are based on non-Indigenous concepts of health and healing (Stewart, 2008). Addressing the social determinants of mental health could reverse some of the impacts of colonial policies.

2.7 Chapter Summary

This chapter argued that mental healthcare and policy in Canada is dominated by the biomedical model of mental illness. It discussed how the history of Canada and Ontario's mental

healthcare policy has been shaped by Medicare, funding, neoliberalism, institutionalization, deinstitutionalization, the Mental Health Act, and policy reforms. The biomedical model of mental illness has been promoted by the pharmaceutical industry through the diagnostic and statistical manual, government, research, regulation, healthcare professionals, consumer groups, and the media. The biomedical model has be criticized for focusing primarily on biomedical treatment, individualizing mental health problems, not taking the perspectives of individuals experiencing mental health into account, promoting Western concepts of mental health, and ignoring the impacts of colonial policies.

CHAPTER 3: A REVIEW OF MAD ADVOCACY

3.1 Introduction

This chapter will outline the experiences of mental health service users discussed in the literature and their advocacy efforts to improve mental healthcare and policy in Canada. The chapter will start by discussing the negative experiences of mental health service users who have used mental healthcare services that align with the biomedical model of mental illness. Mad Studies will be explored as an alternative to the biomedical model of mental illness. The final section will outline mad resistance and initiatives.

The theoretical lens used in this chapter is Mad Studies. The term mad has been reclaimed by people experiencing mental distress as way to take back language that has been used to oppress them (Menzies et al., 2013; Pilling, 2022). The term madness is used by mad people to name emotional, spiritual, and neuro diversity (Menzies et al., 2013). Mad Studies prioritizes the experiences and knowledge of mad people and it aims to change oppressive language, practices, ideas, laws, practitioners, and systems (Burstow, 2013; Gorman & LeFrancois, 2017; Menzies et al., 2013). This field of scholarship seeks to give mad authors control over the definition of madness and challenges narratives of madness in the mental healthcare system and how it impacts mad people (Johnston et al., 2023). Mad Studies tries to understand individuals experiencing mental distress within their social and economic contexts in a way that is humanitarian and holistic (Daley et al., 2019; Menzies et al., 2013). Mad writers encourage us to think about how society and circumstances make people mad since understanding and responding to mental distress requires knowledge of the contexts in which distress emerges (Beresford, 2020; Eromosele, 2022). Many mad people tend to connect their distress to social causes including poverty, isolation, and stigma instead of biomedical causes (Beresford, 2020). Advocates have been working with governments, stakeholders, media, and the

public to change the mental health discourse from the biomedical model to one of social provision, human justice, and diversity (Menzies et al., 2013). Within Mad Studies, there are some proponents who want to legitimize different forms of consciousness that accompany what is pathologized as illness and some proponents work totally outside of the mental healthcare system and framework.

3.2 Perspectives of Mental Health Service Users

3.2.1 Overemphasis on the Biomedical Model

Although not all mental health service users disagree with or dispute the biomedical model, there are some people who believe there is too much focus on this model within mental healthcare. Some mental health service users feel that mental healthcare professionals turned their mental crisis into a mental illness label which left them feeling dehumanized and it also downplayed the significance and intensity of their mental health crisis (Barnetz & Gefen, 2022; Pilling, 2022). Barnetz & Gefen (2022) interviewed mental health survivors who said mental healthcare professionals are too fixated on labels and cures that they ignore the individual and their unique experiences and circumstances. Some mental health service users were disappointed when they were not provided treatment options other than medications since medications can be ineffective and have harmful side effects (Armstrong et al., 2018; Barnetz & Gefen, 2022; Johnston et al., 2023). Some mental health survivors feel that medications are used to silence them by making them apathetic so that they do not speak up or resist (Barnetz & Gefen, 2022).

3.2.2 Experiences of Power Imbalances

There is a power imbalance that occurs because mental healthcare professionals are viewed as having power and control over mental health service users and their treatment (Pickett et al., 2012). Psychiatric power is structured in a way that privileges mental healthcare

professionals by considering them experts because their knowledge is supposed to be objective whereas the knowledge of mental health service users is disregarded because it is subjective (Pilling, 2022). Psychiatrists also have power within the Canadian mental healthcare system because they are the only publicly funded mental healthcare professionals (Goering et al., 2000). Researchers have found that mental health service users tend to feel hesitant about making requests and psychiatrists are not always able to identify what the person wants which leads to differences in expectations and power struggles and can also cause mental health service users to be reluctant to ask questions (Armstrong et al., 2018; Pickett et al., 2012).

Armstrong et al. (2018) noticed that youth in their study who sought treatment through a first episode mood and anxiety program felt uncomfortable, disempowered, and misunderstood which made it difficult for them to advocate for themselves. Ross et al. (2018) found that lesbian, gay, bisexual, trans, and/or queer (LGBTQ) people can view the mental healthcare they receive as unhelpful and unsafe if they do not have control and are not able to express their opinions. Advocates suggest that mental health consumers and mental healthcare professionals should work together to develop treatment plans to give mad people power, authority, and control over their treatment (Pickett et al., 2012). Empowering mental health consumers has shown to lead to increased self-esteem, self-efficacy, confidence, optimism about the future, treatment compliance, and satisfaction (Pickett et al., 2012).

3.2.3 Time Constraints and Rushed Care

Researchers have found that some mental health service users felt that mental healthcare professionals were not spending enough time with them when they were providing care. Stenhouse (2011) in their study of patient expectations and experiences of help on an acute psychiatric inpatient ward found that patients were expecting to receive help for their problems

by interacting with nurses, but the nurses seemed too busy to spend time with them. Nurses initially told patients they could come talk to them anytime but then were too busy to talk (Stenhouse, 2011). Studies suggest that when patients felt that mental healthcare professionals were rushed and inaccessible, it made them feel disrespected and they felt like an inconvenience when mental healthcare professionals expressed how busy they were (Armstrong et al., 2018; Digel Vandyk et al., 2018).

3.2.4 Feeling Unheard and Overlooked

Pilling (2022) found that mad, queer, trans, and Black, Indigenous, and people of colour (BIPOC) who used mental health services felt that mental healthcare professionals were not listening to them when they accessed mental healthcare services. Johnston et al. (2023) also found that individuals accessing psychiatric care felt that their psychiatrist did not take the time to get to know them or listen to their concerns which prevented the psychiatrist from properly understanding their distress. The individuals accessing psychiatric care questioned why the psychiatrist used a questionnaire to determine whether or not to increase their medication when the psychiatrist should have just listened to their words and feelings (Johnston et al., 2023). Barnetz & Gefen (2022) found that some mental health survivors who were hospitalized also felt that their wishes were not taken into consideration. Some mental health service users had negative experiences when services were rigid and their feedback was not taken into account and they were less likely to comply with their treatment when they felt that their opinions were ignored (Kerman et al., 2019; Pickett et al., 2012). Mental health survivors tend to want service providers who are understanding, recognize that they are part of a system that silences and erases people, and someone to sit down with them who they can talk to and who will explain things to them (Barnetz & Gefen, 2022).

3.2.5 Encounters with Discrimination

Mental healthcare professionals have been shown to exhibit prejudice towards individuals labelled as mentally ill (Fabris, 2013). Mad, queer, trans, and BIPOC people experienced discrimination and prejudice when accessing mental healthcare services which was exacerbated when they had intersecting identities such as queer and racialized (Pilling, 2022). For instance, Pilling (2022) describes how a South Asian, queer, cisgender woman was asked by counsellors to validate racist stereotypes about brown people that she did not agree with. The experience of facing prejudice and discrimination can worsen health and unmet needs since they create barriers to accessing services (Marchand et al., 2016). Individuals with co-occurring mental disorders are also more likely to experience prejudice and discrimination (Marchand et al., 2016). Mental healthcare professionals were perceived negatively by mental health service users when they were disrespectful, judgmental, and lacking compassion because mad people tend to want to avoid judgement (Barnetz & Gefen, 2022; Kerman et al., 2019).

3.2.6 Persistent and Unmet Needs

Mental health service users in Canada have unmet needs because there are significant gaps in publicly funded supports and they are short-term (Ross et al., 2018). Kerman et al. (2019) found that homeless people with mental health problems had negative experiences when their needs were not met such as needs for housing or services related to physical or mental health. Services that do not provide adequate treatment or care lead to worsening health, discontinuing services, and avoiding services in the future (Kerman et al., 2019). Mental health service users need to work hard to take care of themselves without the support of the mental healthcare system since they understood the shortcomings of the system and realized that they would have to create their own support systems and engage in activism (Barnetz & Gefen, 2022; Ross et al., 2018).

3.3 Foundations of Mad Studies

The anti-psychiatry movement advocates for the abolition of psychiatry and was led by academics and psychiatrists who wanted to highlight the abuse of psychiatry and change its practices (Morrow, 2017; Reaume, 2022). Mad people also joined the anti-psychiatry movement, but the movement was not started by people who identified as mad and mad identifying people also developed groups outside of anti-psychiatry (Reaume, 2022). Feminists developed a critique of patriarchy that criticized psychiatry for framing women as weak and fragile (Morrow, 2017). In the 1970s, deinstitutionalization allowed patients who were discharged from hospitals to share their stories of abuse and there was also public criticism of institutionalization (Morrow, 2017; Reaume, 2022). The mental patient's liberation movement was led by people who had been harmed by psychiatry and they developed organizations and programs for former patients, magazines, websites, blogs, conferences, and networks which critiqued psychiatry and mental healthcare (Morrow, 2017; Reaume, 2022). Morrow (2017) suggests that, "The feminist movement, the anti-psychiatry movement, and the mental patients' liberation movement have all played pivotal roles in critiquing the psychiatric paradigm and the medical model of mental illness, exposing the abuses of psychiatry and challenging its claims to objective knowledge".

There have been significant criticisms of psychiatry from feminists. Bonnie Burstow argued that electroconvulsive therapy is a form of violence against women (Burstow, 2006). Women are 2 to 3 times more likely to be subjected to electroconvulsive therapy than men and 95% of electroconvulsive therapy doctors are male (Burstow, 2006). Burstow (2006) argues that electroconvulsive therapy damages the brain, causes memory loss, and intellectual impairment without improving patient outcomes. Women received electroconvulsive therapy when they experienced distress related to sexual abuse, physical abuse, postpartum depression, depression,

marital problems, and sexual preferences (Burstow, 2006). Electroconvulsive therapy is used to punish, threaten, and silence women in order to achieve social control, enforce gender roles, and enforce heterosexuality (Burstow, 2006). Paula Caplan and Kade Patterson are feminists who have written about the harms of receiving a mental illness diagnosis, especially for women (Caplan & Patterson, 2015). They argue that mental illness diagnosis tends to be entirely unscientific, does not reduce the suffering of individuals who are diagnosed, and causes harms including decreased self-confidence, job loss, difficulty getting a job, losing custody of children, and losing rights to make decisions about medical and legal matters (Caplan & Patterson, 2015). Some women are diagnosed with a mental illness when they are having normal reactions to traumatic events such as being raped (Caplan & Patterson, 2015). The mental illness diagnosis is used to discredit and silence these women (Caplan & Patterson, 2015).

The contemporary mad movement started during the 1960s and 1970s which was a time when psychiatry was undergoing major changes due to deinstitutionalization and the rise of medications to treat mental illnesses (Aftab et al., 2023; Menzies et al., 2013). Mad Studies was started by mad people and their allies who wanted to empower and engage with individuals who had direct experience with psychiatry (Reaume, 2022). Mad Studies is a field of scholarship, theory, and activism related to the lived experience of people who identify as mad, their history, culture, and politics (Beresford, 2020; Gorman & LeFrancois, 2017). Mad people fought against the dominant narrative that they have chemical imbalances that need medical treatment since madness is not conceptualized as an illness within Mad Studies and they wanted to provide alternatives to biomedical models of treatment (Menzies et al., 2013; Redikopp, 2021). Mad Studies highlights how everyday experiences and normal ranges of feelings have been pathologized and allows us the possibility of cherishing the full range of human emotion

(Redikopp, 2021).

3.4 Expressions of Mad Resistance

The recovery movement originated in the United States in the late 1980s by mental health service users who wanted to regain control of their lives after having it taken away by psychiatric power (Tang, 2022). The recovery movement starts with the lived experience and knowledge of people experiencing mental distress and advocates for shifting power from mental healthcare professionals to mad people (Tang, 2022). The recovery approach is used by critical groups as an alternative to biomedical treatment since the biomedical model frames people as either ill or healthy whereas recovery can exist over a spectrum (Barnetz & Gefen, 2022). The recovery approach rejects medical terms such as symptoms, illness, pathology, and cure and asserts that recovery does not necessarily require medications, is possible regardless of diagnosis, and a person diagnosed with a mental illness will not be mentally disturbed or require medication for the rest of their life (Barnetz & Gefen, 2022; Chambers, 2008). Recovery is about improving the quality of life of mad people so that they can function and manage their lives while experiencing mental distress (Barnetz & Gefen, 2022). Recovery focuses on how people are able to rebuild a worthwhile life and positive identity regardless of their diagnosis or symptoms (Brown & Wituk, 2010; Johnston, 2020). Recovery occurs when mental health service users reinvent their lives with them in charge and live their life according to what recovery means to them (Chambers, 2008).

People think of recovery in different ways based on where they are located within the mental healthcare system (Poole, 2008). Mental healthcare professionals believe that biomedical treatment leads to recovery and that recovery can be tracked and tested (Johnston, 2020; Poole, 2008; Wilson, 2008). Biomedical recovery focuses on symptom remission and the use of

medications to eliminate symptoms (Barnetz & Gefen, 2022; Tang, 2022). The recovery approach promoted by mental health service users who are resisting the biomedical model of mental illness requires mental healthcare professionals to see people with mental illnesses as more than an illness and understand what the person is recovering from whether it be poverty, trauma, stigma, or demoralization (Priest & O'Hagan, 2008). Hence, recovery should not be left to healthcare professionals to define (Tang, 2022).

Mad resistance occurs when mad people resist the biomedical model of mental illness and psychiatric powers in their day to day lives. Resistance allows mad people to regain control, improve self-respect, feel empowered, and become activists (Barnetz & Gefen, 2022; Skorpen et al., 2008). Mad people showed resistance within psychiatric institutions when they broke the rules, recorded the bad behaviour of staff, found ways to maintain their dignity when they were restrained, and created safe spaces for themselves (Barnetz & Gefen, 2022; Skorpen et al., 2008). An example of a safe space within a psychiatric institution is the smoking room where patients could practice self-help, peer support, help ensure each other's needs were met, and they could engage in activities without being observed (Skorpen et al., 2008). Some mad people recognize that their needs are not being met within the mental healthcare system, so they engaged in social activism in order to address unmet needs (Barnetz & Gefen, 2022).

Mad resistance also occurs when mad people use their voice to criticize the biomedical model of mental illness, the mental healthcare system, and psychiatric powers. Mad people resist the mind/body dichotomy created by the biomedical model of mental illness and instead prompt us to understand how the mind and body are interconnected, mad people resist being labelled mentally ill by creating their own language such as using the term "mad", and mad people resist being pathologized by helping others understand that mental distress is a rational response to

challenging circumstances (Johnston et al., 2023; Pilling, 2022). Psychiatry focuses on compliance rather than individual decision making and frames non-compliance as deviant or a symptom of mental illness so mad people resist through organized non-compliance which is consciously acting in ways to reclaim power and promote social change (Tosh, 2017). Mad people resist online when they use "ratemds" to express concerns about doctors, reject psychiatric practices, and provide information that normally gets discredited due to power imbalances in the mental healthcare system (Johnston et al., 2023). Social media activism on Twitter allows mad people to resist dominant representations of mental illness by sharing their experiences to demonstrate that mental illness might not look the way you expect it to (Koteyko & Atanasova, 2018).

Another form of mad resistance occurs when mad people share their stories because it allows them to recover their voice (Koteyko & Atanasova, 2018). Unfortunately, mental healthcare organizations sometimes absorb stories, sanitize them, and use them in ways that are useful to them without disrupting harmful dominant practices (Costa et al., 2012; Voronka, 2017). Mental healthcare workers highlight stories that do not implicate them in oppression, injustice, and discrimination (Costa et al., 2012; Fabris, 2013). Mental healthcare organizations have favoured uplifting stories that focus on how use of services, medications, hard work, perseverance, and pursuing a productive life saved the individual's life (Costa et al., 2012). Mad people with radical opinions are not recruited to speak, which leads to some lived experiences not being widely discussed within the mental health system and prevents real change from occurring to address issues such as poverty, unemployment, and discrimination (Costa et al., 2012). Stories need to be recovered so that they challenge the biomedical model and highlight

the social, economic, political, environmental, and cultural contexts that lead to mental distress (Costa et al., 2012; Voronka, 2017).

3.5 Mad-Led Initiatives

3.5.1 Initiatives Focusing on Individuals

I am using the term mad initiatives to identify initiatives that are started by mental health service users and their allies to help people experiencing mental distress meet their needs. These initiatives move beyond biomedical treatment although they are sometimes co-opted by the mental healthcare system. These initiatives help mental health service users develop skills, build connections, provide information and resources, and help people access treatment, housing, food, and employment.

3.5.1.1 Self-Help

Any self-directed activity that leads to personal improvement is referred to as self-help (Brown & Wituk, 2010). The aim of self- help initiatives are to enhance the coping skills of people struggling with mental distress and help them progress towards recovery (Brown & Wituk, 2010). The self-help movement in mental health began in the 1970s after deinstitutionalization when ex-patients and parents of people experiencing mental distress criticized the mental healthcare system and began to develop self-help initiatives and advocate for the rights of mad people (Brown & Wituk, 2010). Self-help groups are based on principles of empowerment, inclusion, non-hierarchical decision making, shared responsibility, and understanding of people's cultural, economic, and social needs (Brown & Wituk, 2010). Self-help groups are an important part of people's recovery and complement the mental healthcare system (Morselli, 2000). It has been argued that self-help initiatives can help mad people in their

recovery, provide advice and information, help them develop coping skills, provide emotional and social support, prevent suicides, access treatment, integrate into community, expand their networks, reduce isolation, empower them, give them an avenue to help others, develop skills, provide positive role models, take control of their life, instill hope and positive self-image, provide resources, help develop better working relationships with mental healthcare professionals, help destigmatize mental illness, and lead to a better understanding of mental illness (Bayers, 2008; Brown & Wituk, 2010; Morselli, 2000). Online self-help groups reduce barriers to participation, offer anonymity and equality, and allow members to access support and information at any time, even without actively contributing (Brown & Wituk, 2010)

3.5.1.2 Peer Support

Peer support helps eliminate the hierarchies and unequal power dynamics that can exist in the mental healthcare system by allowing people who experience mental distress to connect with peers. Peer support workers are people with lived experience with mental distress (Fawm, 2008). Peer support involves a relationship between individuals who have similar characteristics and experiences and who are open to acknowledging and sharing those experiences (Brown & Wituk, 2010). Peer support workers can connect with people experiencing mental distress in ways that mental healthcare professionals cannot (Voronka, 2017). Peer support workers are considered experts because of their experience, and they provide services and supports to people who are struggling with mental distress (Voronka, 2017). Peers can act as role models who normalize the experience of mental distress, inspire hope, provide alternative ways of thinking and behaving, and demonstrate that you can live successfully and productively in the community while experiencing mental distress (Brown & Wituk, 2010; Voronka, 2017; Wilson, 2008). Being exposed to other people who have overcome their mental distress is the first step to believing in

one's own capacity to do the same (Wilson, 2008). Peer support can help people understand their strengths, potential, and their problems in the social and political contexts they live in rather than pathologizing themselves (McKinnon, 2008).

Peer-led programs provide patients with resources, emotional support, opportunities for sharing knowledge, and social support (Pickett et al., 2012). By establishing a safe connection with a peer support worker, consumers and survivors can feel more confident in seeking other connections within the mental healthcare system and community (Harrington, 2008). Peers can develop therapeutic relationships with each other and provide support which can lead to decreased hospitalization, improved quality of life, fewer life problems, and improved social functioning (McKinnon, 2008). Peer support employment opportunities have led to personal and professional growth, increased financial resources, and increased self-satisfaction (McKinnon, 2008). The peer support relationship allows the person who is being helped to regain control over their goals, desires, and needs (Wilson, 2008). Peer support acknowledges that recovery is a personal choice and that there should not be any hierarchy in the peer-to-peer relationship (Wilson, 2008). The peer support worker is just as likely to learn and benefit from the relationship as the person who is being helped (Wilson, 2008).

When peer support work was adopted by mental healthcare systems it was criticized as aligning with the biomedical model of mental illness. Peer support workers can embody the goals of neoliberal and biomedical projects by encouraging people with mental health issues to feel and respond in ways that encourage compliance and cooperation with “psy sciences” (Voronka, 2017). Peer support work can be a new and less costly way to encourage people who are struggling with mental health issues to govern themselves (Voronka, 2017). Peer support workers are asked to use their labor to govern people who are like them while challenging

psychiatric powers remains outside of their job description (Voronka, 2017). Peer support workers can also be subject to the same stigma as any other mad individual which can lead to them losing opportunities and income (Fabris, 2013). Peer support workers are trying to fight for change within a system where other mental healthcare professionals and "psy powers" do not want change which can lead to dangerous situations and create more confusion within a broken system (Fabris, 2013). Peer support work is problematic when it focuses on madness instead of the larger structural issues that need to be addressed (Voronka, 2017).

3.5.1.3 Consumer Survivor Run Organizations

Consumer survivor organizations have played a crucial role in Ontario's mental healthcare system by supporting people in recovery (Canadian Mental Health Association, 2005). The term consumer is used politically to refer to people who used mental health services to emphasize their role as active participants with rights, choice, and a voice in care rather than passive patients. Consumer survivor organizations are run by and for consumers and survivors and are based on the principles of inclusiveness, recovery, empowerment, peer advocacy, and peer support (Brown & Wituk, 2010; Canadian Mental Health Association, 2005). Consumer survivor organizations are considered best practice and the government of Ontario provides funding for them (Reville, 2008). In 1991, the government of Ontario started a $3 million consumer survivor development initiative which provides funding for 42 self-help organizations (Reville, 2008). These initiatives were designed to utilize the skills and knowledge of consumers and survivors (Reville, 2008). Consumer and survivor organizations such as Working for Change are still operating but these organizations have not received any new substantial investments, some have lost their funding, and some have lost their organizational autonomy (Canadian Mental Health Association, 2005; Working for Change, 2023).

Consumer survivor run organizations help to increase awareness about mental illness, do advocacy work, outreach, provide social support, and opportunities for leadership (Brown & Wituk, 2010). Consumer survivor initiatives consist of peer support, alternative businesses, and other empowerment models (Canadian Mental Health Association, 2005). Consumer survivor initiatives offer employment, training, and volunteer opportunities which help survivors improve their self-esteem and their expectations about the future (Canadian Mental Health Association, 2005). Consumer survivor initiatives give consumers and survivors an opportunity to give back to the community (Canadian Mental Health Association, 2005). Consumer and survivors benefit from seeing consumer survivor initiatives because it shows them that consumers and survivors are perfectly capable of running their own organizations and having a voice (Canadian Mental Health Association, 2005). People who participate in consumer survivor initiatives have fewer symptoms related to distress, use fewer crisis services, are institutionalized less often, and use less medication. (Brown & Wituk, 2010; Canadian Mental Health Association, 2005). Participating in consumer run organizations can strengthen coping skills, enhance empowerment, increase confidence, and increase social support and networking (Brown & Wituk, 2010). All of these improvements help with recovery (Brown & Wituk, 2010).

Consumer run drop-in centres provide consumers and survivors with peer support, leadership opportunities, address social isolation, and stigma (Brown & Wituk, 2010). These centres provide educational activities, host support groups, do advocacy work, provide education to the public about mental illnesses, and participate in community projects (Brown & Wituk, 2010). Drop-in centres provide consumers and survivors with a laundry facility, kitchen services, social activities, peer support, holiday events, and workshops (Fawm, 2008). Participants benefit from consumer run drop-in centres by giving and receiving support, they have better social

functioning, more coping strategies, more social support, improved quality of life, and decreased hospitalization (Brown & Wituk, 2010). Consumers and survivors felt that consumer run drop-in centres provided support and caring, they felt accepted, and they used the centre based on their own choices (Brown & Wituk, 2010). They also had an increase in volunteer work, paid employment, school involvement which decreased their institutionalization, substance use, and use of traditional mental healthcare services (Brown & Wituk, 2010).

Consumers and survivors believe that these initiatives provide a respite from mental healthcare professional involvement in their life and a place where they are seen as people first instead of just recipients of care (Canadian Mental Health Association, 2005). Consumer survivor initiatives can be the first place where consumers and survivors feel control over what happens to them, they address unmet needs, and they provide consumer and survivors with choices regarding services and support (Canadian Mental Health Association, 2005; Reville, 2008). Consumer survivor initiatives provide services when people are not able to access hospital or community mental health agencies due to long wait lists, clinical intake processes, or exclusionary criteria (Canadian Mental Health Association, 2005). Consumer survivor initiatives are open to people who do not want to access traditional mental healthcare services (Canadian Mental Health Association, 2005). People can join consumer survivor organizations at any time and usually at no cost which alleviates pressure on other mental healthcare services (Reville, 2008).

3.5.2 Collective Organizing and Advocacy

Collective organizing and advocacy have played a critical role in reimagining and reforming the mental healthcare system in Ontario. Advocacy groups are comprised of mental health service users and their allies who aim to transform policies, practices, and legislation that

often perpetuate stigma, marginalization, and medicalized understandings of mental distress (O'Hagan, 2010). These groups provide alternative models of care that are grounded in lived experience, peer support, and principles of social justice (O'Hagan, 2010). Examples of advocacy groups in Ontario are discussed below. These examples are different from the ones provided in the previous section because they primarily focus on improving systems whereas the initiatives primarily focus on improving the daily lives of mental health service users.

Collective organizing provides a vital platform for individuals with lived experience to connect with peers who have encountered similar challenges within the mental health system (Voronka, 2016). These spaces enable the exchange of experiential knowledge, promote solidarity, and facilitate the development of community-based responses that are non-coercive (Russo, 2022). Moreover, this form of advocacy challenges the passive positioning of mental health service users within mental healthcare by fostering leadership, collective resistance, and policy engagement (Beresford & Croft, 2001). Through public education, storytelling, protest, and academic collaboration, mental health service users are reclaiming agency and redefining what meaningful, ethical, and inclusive care should entail (Morrow, 2017; Reaume, 2022; Voronka, 2016).

3.5.2.1 Mad Students Society

Landry (2023) has written about the origins and purpose of the Mad Students Society in Ontario which ran from 2005 to 2015 as a peer support and advocacy group for mad students (Landry, 2023). The Mad Students Society met monthly and moderated an active, private, email discussion listserv open to members living anywhere in the world (Mad Students Society, n.d.). The vision of the Mad Students Society was to create a community of empowered mad students who were aware of the history of the psychiatric survivor movement and who would support one

another (Landry, 2023). The Mad Students Society gave presentations and workshops, tabled at events, wrote letters, gave interviews, and attended marches as part of their advocacy related to mad student issues (Landry, 2023). The Mad Students Society did not have any staff, barely had any funding, and was operated by mad students (Landry, 2023).

Members of the Mad Students Society created methods of resistance to respond to issues impacting their lives even when those issues fell outside of student life (Landry, 2023). Members of the Mad Students Society wanted more accessible education and believed that post-secondary institutions should be flexible so that students can return or start education later in life (Landry, 2023). The Mad Students Society challenged the medicalization of accommodation policies and practices and wanted accommodation offices to have standardized policies across institutions (Landry, 2023). There was a lack of transparency with student accommodations, so a listserv was created to discuss student accommodations (Landry, 2023). The members of the Mad Students Society learned to respect and accommodate each other's access needs by participating in mutual aid (Landry, 2023). They respected each other's confidentiality, advocated for one another and themselves, learned how to navigate university administration and bureaucracy, and offered peer support by watching it be role modeled by other mad students, and created a community (Landry, 2023). Their advocacy led to some incremental institutional changes (Landry, 2023).

3.5.2.2 Ontario Psychiatric Patient Advocate Office

The Psychiatric Patient Advocate Office was launched by the Ontario government in 1983 to protect the rights and entitlements of patients in provincial psychiatric hospitals and was established largely as a result of advocacy efforts (Kehyayan, 2008). The Psychiatric Patient Advocate Office gives a voice to patients and ensures that their wishes and needs are heard by mental healthcare professionals and policymakers (Kehyayan, 2008). The Psychiatric Patient

Advocate Office helps patients in their self-advocacy efforts so that they can achieve their desired outcomes (Kehyayan, 2008). The Psychiatric Patient Advocate Office provides rights advice in psychiatric hospitals, general hospitals with mental health units, and to individuals on community treatment orders (Kehyayan, 2008). Skilled advocates and rights advisors can help patients have timely access to supports and receive optimal care (Kehyayan, 2008). The office provides legal representation for patients and deals with complaints related to daily living in institutions and community settings (Prowse, 2008). The Psychiatric Patient Advocacy Office distributes posters, brochures, and provides verbal communication to patients, families, and others about patient rights (Prowse, 2008). The Psychiatric Patient Advocate Office is still in operation.

The Ontario Association of Patient Councils was created in 1993 to share challenges, knowledge, and provide clear messages about issues that are important to patient councils, and patients (Claxton, 2008). Patient councils are based on empowerment, peer advocacy, and peer support (Claxton, 2008). Everyone involved in patient councils are people who have had personal experience with the mental healthcare system (Claxton, 2008). Patient councils provide patients an opportunity to connect with people who have had similar experiences since they can understand one another's situation through empathy and shared emotional experiences (Claxton, 2008). Patient councils provide a voice for consumers and survivors in institutional settings, advocate for improvements in quality care, patient safety, respect for patient rights, promote recovery, provide immediate support, engage in advocacy, provide education and training for stakeholders, engage in community development, conduct research, create stigma reduction and public education programs, and provide opportunities to socialize for patients (Claxton, 2008). The Patient and Family Advisory Council is currently operating in Ontario.

3.5.2.3 Empowerment Council at the Centre for Addictions and Mental Health

The Empowerment Council was founded in 2002 and built on the decade long advocacy of the Queens Street Patient Council (The Empowerment Council, 2024). The Empowerment Council advocates on behalf of individuals who have accessed mental health or addiction services in ways that most effectively meet their self-identified needs (The Empowerment Council, 2024). The Empowerment Council consists of members, board, and staff who are currently or have previously accessed mental health or addiction services in order to ensure the involvement of clients in decision making, accountability structures, committees, focus groups, task forces, outreach, and community development (The Empowerment Council, 2024). The Empowerment Council provides information and education to clients, mental health and addictions service providers, students, members of the public, and others to advocate for systemic change which involves changing policies, practices, and laws that impact how clients experience the mental healthcare system (The Empowerment Council, 2024). The Empowerment Council's advocacy priorities are human rights and ethics, changing policy and practice, seeking justice, client leadership, client knowledge, meaningful engagement with clients, research, and community solidarity and partnerships (The Empowerment Council, 2024). The Empowerment Council is still in operation.

3.6 Chapter Summary

This chapter has outlined the experiences of mental health service users and their advocacy efforts to improve mental healthcare and policy. The negative experiences of mental health service users was discussed when they used mental healthcare services that aligned with the biomedical model of mental illness. Mental health service users had negative experiences when there was too much focus on biomedical treatment, there were power imbalances, mental

healthcare professionals did not spend enough time with them, mental healthcare professionals did not listen to them, they faced discrimination, and their needs were not met. Mad Studies was explored as an alternative to the biomedical model of mental illness. Mental health service users' acts of resistance to psychiatry and compliance were discussed. Resistance occurred in smoking rooms, by rating doctors online, through social media, and by recovering stories. Mad initiatives such as self-help, peer support, and consumer survivor run organizations were focused on. Mad organizing and advocacy such as the Mad Student Society, Ontario Psychiatric Patient Advocate Office, and the Empowerment Council at the Centre for Addiction and Mental Health were highlighted. A further area to explore is mental health service users' experience of doing advocacy work to improve mental healthcare and policy in Ontario.

CHAPTER 4: METHODOLOGY

4.1 Overview

A qualitative research design was used to investigate the main research question: What is the mental health service user experience of engaging in advocacy work aimed at improving mental healthcare and policy in Ontario? This question was answered by conducting semi-structured interviews with mental health service users who have accessed mental health services in Ontario and who have engaged in advocacy work in Ontario to improve mental healthcare and policy. Research participants also completed an online demographic survey through Qualtrics which is a cloud-based software platform used to create surveys, collect data, and analyze experiences. Questions included in the survey asked participants about their age, location, sex, gender identity, sexual orientation, race/ethnicity, education, employment status, and household income to help to understand the relationship between demographics and people's advocacy experiences. An attempt was made to recruit mental health service users from diverse backgrounds and across Ontario from different size cities.

4.2 Research Paradigm and Theoretical Orientation

A constructivist and Mad Studies approach was used for this research study (Lincoln & Guba, 2005). The constructivist paradigm has a relativist ontology because it assumes that reality is socially constructed, local, and specific (Labonte & Robertson, 1996). Constructivist epistemology assumes that what we can know about reality is constructed and co-created among individuals and knowledge can be achieved through consensus (Labonte & Robertson, 1996). Constructivist methodology involves dialogue between individuals and comparing different interpretations of reality (Labonte & Robertson, 1996). The aim of inquiry is to understand the lived experiences of individuals within their social and historical contexts (Lincoln & Guba,

2005). Knowledge can be used for social emancipation and a call to action which is intrinsically valuable (Lincoln & Guba, 2005).

This approach fits with the theoretical lens of Mad Studies because it focuses on the lived experience of mental health service users in Ontario. The findings of the research are based on knowledge that has been shared by mental health service users and synthesized by the researcher. The knowledge generated from this research study can be used as a call to action to improve mental healthcare and policy in Ontario.

4.3 Participant Recruitment

Non-probability and snowball sampling was used for this research study. Key informants were identified and asked to recommend mental health service users to participate in the research study. An ad was posted on Mad Studies and advertising websites listed in Appendix A. A recruitment email was sent to mental health organizations, hospitals, and university departments in Ontario that are listed in Appendix A. The most successful recruitment strategies were key informants, an ad through the Mad Studies Hub at York University, and recruitment emails to university departments. These recruitment strategies were likely successful because the people identified through these strategies are already involved in research and value knowledge creation. Mental health service users were recruited who were above the age of 18, from diverse backgrounds, and different size cities in Ontario. Twenty mental health service users were recruited over the course of several months. Ten to twenty knowledgeable people are usually enough to uncover and understand the core categories in a well-defined study of lived experiences and to reach saturation (Bernard, 2013).

4.4 Data Collection: Surveys and Interviews

Research participants were asked to complete an online demographic survey through Qualtrics and twenty participants completed the survey. The survey questions focused on age, location, sex, gender identity, sexual orientation, race/ethnicity, education, employment status, and household income. The survey questions can be found in Appendix B. One on one semi-structured interviews were conducted with twenty research participants over Zoom. Interviews over Zoom provided better access to participants across Ontario than in-person interviews. Interviews were transcribed using Otter.ai an AI-powered transcription software. An open-ended interview guide was used which can be found in Appendix C. Questions focused on participants' advocacy journey, advocacy work, personal and systemic challenges, facilitators and enablers, rewards, impacts, promising approaches for improving mental healthcare and policy, policy mechanisms, and recommendations. The open-ended questions allowed participants to provide thick descriptions of their experiences. The interview guide included a written list of questions and topics that needed to be covered in a particular order during the interview. The questions in the interview guide were formulated by the researcher and reviewed and revised by the supervisor before the interviews began. Research participants were emailed the interview guides before the interview.

4.5 Coding Process

Ryan and Bernard (2003) outlined the thematic analysis approaches and techniques that were used to analyze the data. This approach was chosen because it fit with the aims of the research study where key themes could be linked to the theoretical framework of Mad Studies. The following four tasks were completed: 1) discovering themes and subthemes, 2) winnowing themes to a manageable few, 3) building hierarchies of themes, and 4) linking themes into theoretical models (Ryan & Bernard, 2003). An inductive approach was used to ensure that

themes are strongly linked to the data and derived from participant responses. The repetitions scrutiny technique was used to determine which concepts recur throughout the transcripts (Ryan & Bernard, 2003). Themes were created based on which concepts recurred in the transcripts. The similarities and differences scrutiny technique were used which involves making systematic comparisons across units of data (Ryan & Bernard, 2003). Themes were created based on similarities across transcripts. Minority themes were included if they furthered an understanding of Mad Studies. A line-by-line analysis of the transcripts was completed to ensure that all themes were identified and to reduce researcher bias in identifying themes. The cutting and sorting processing technique was used which involves identifying expressions that seem important and arranging the expressions that go together (Ryan & Bernard, 2003). Themes were reviewed in relation to transcripts in order to collapse or rename them.

4.6 Data Analysis Approach

A Mad Studies lens was applied to the data and participants were asked questions that prompted them to critically assess the mental healthcare system. The analysis prioritized lived experience knowledge and used it to determine promising approaches for improving mental healthcare and policy in Ontario as well as providing recommendations for how to advocate successfully. This fits with the Mad Studies lens because it privileges the knowledge of mental health service users over the knowledge of mental healthcare professionals and challenges dominant narratives about the mental healthcare system. The ethnic and racial backgrounds of participants were highlighted when it influenced their advocacy experiences to address the criticism that Mad Studies silences the voices of racialized individuals by privileging the voices of white individuals (Redikopp, 2021).

CHAPTER 5: FINDINGS

5.1 Introduction

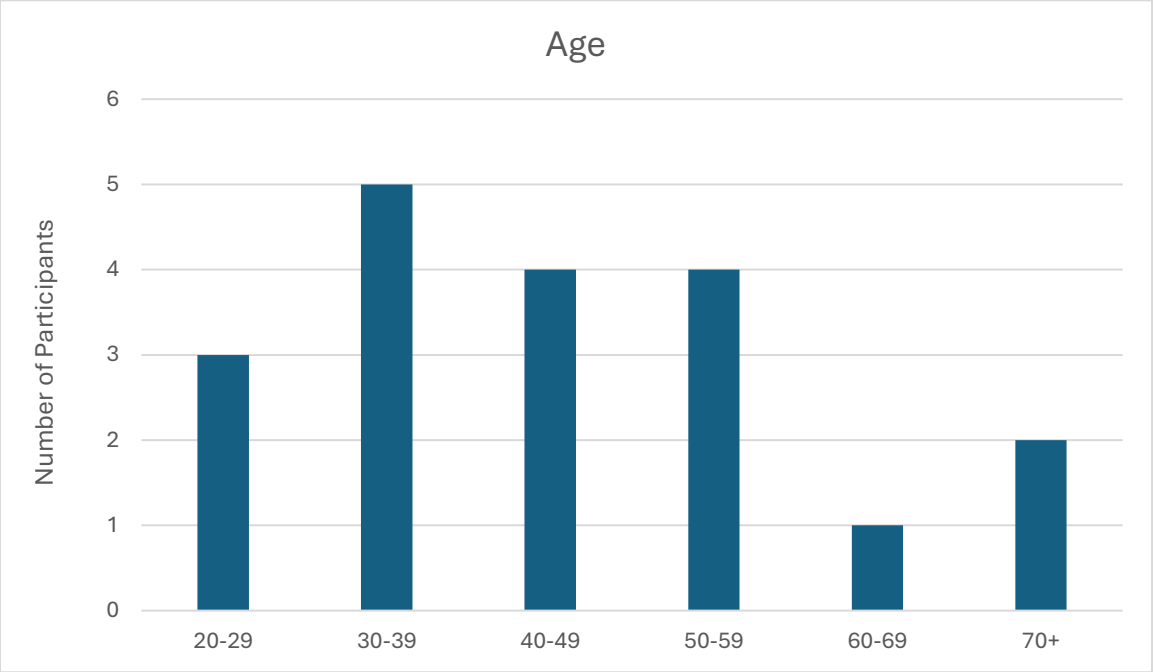
This chapter discusses the findings from twenty demographic surveys and semi-structured interviews. The survey results section highlights the demographics of the participants. The answers from the demographic survey are displayed in charts which show the age, city, sex, gender identity, sexual orientation, ethnicity/race, education, employment status, and household income of the participants. The findings from the interviews are outlined in the next section. The interview findings illustrate participant experiences related to their advocacy journey, advocacy work, personal and systemic challenges, facilitators and enablers, rewards, impacts, promising approaches for improving mental healthcare and policy, policy mechanisms, and recommendations.

5.2 Survey

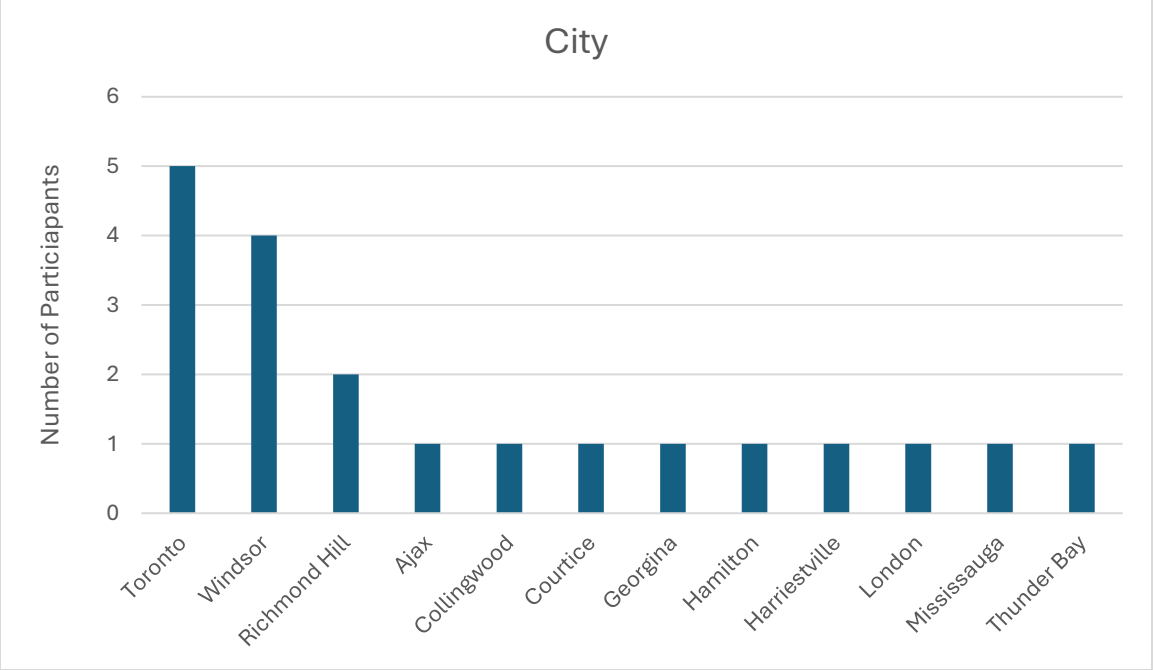
5.2.1 Results

All twenty participants completed the demographic survey which can be found in Appendix B. However, not every participant answered each question because participants were able to skip questions they did not want to answer. In the survey participants were asked to self-identify their gender identity, sexual orientation, and ethnicity/race so the results are displayed according to how participants self-identified.

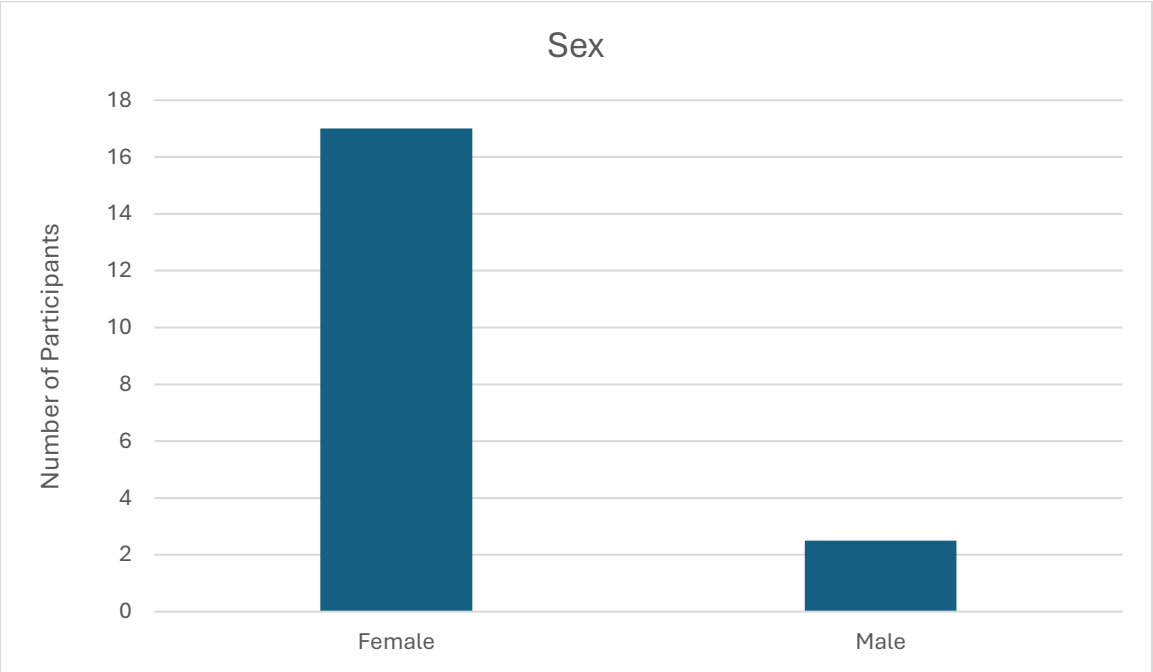
5.2.2 Charts



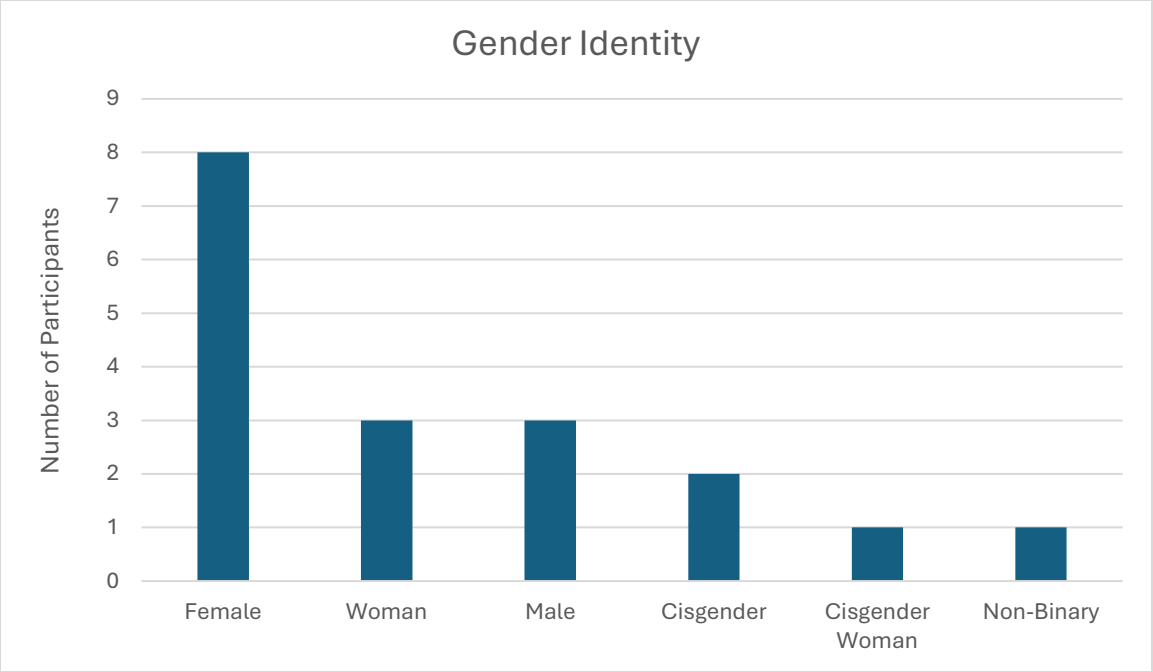
Nineteen participants answered this question. Participants varied in age with the greatest number of participants between the ages of 30-39 (n=5).



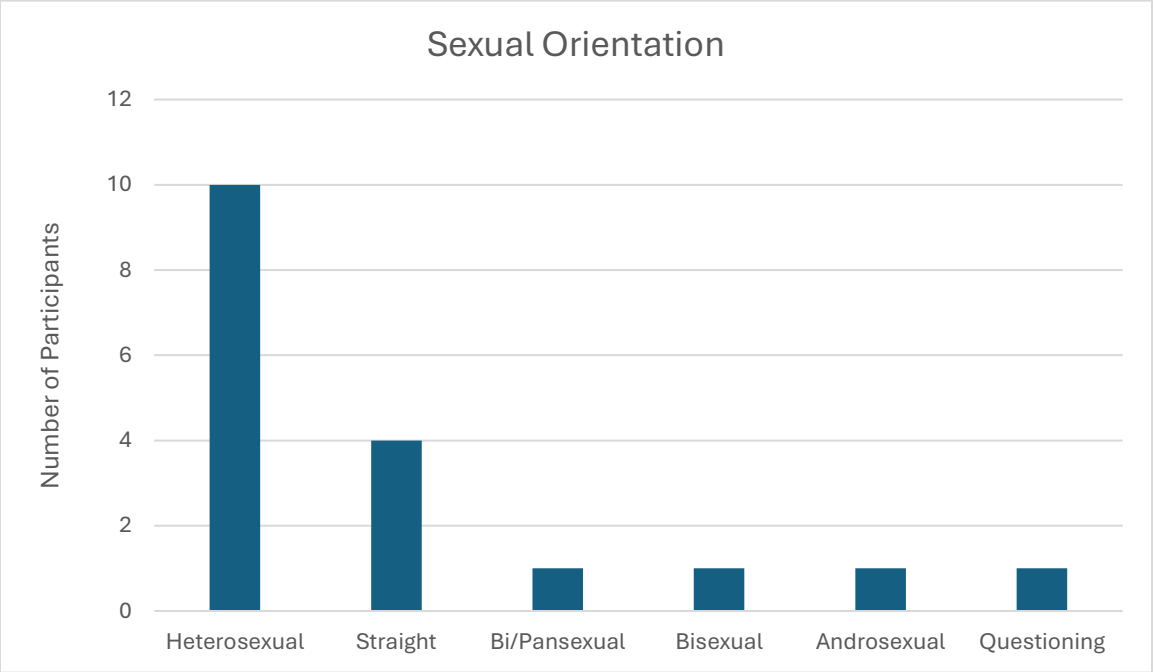
Twenty participants answered this question. Participants were recruited across different cities in Ontario with the greatest number of participants from Toronto (n=5) and Windsor (n=4). This could be due to the fact that a large number of universities and mental health organizations are located in Toronto. A professor from University of Windsor helped advertise the research study to their students which increased the number of participants from Windsor.



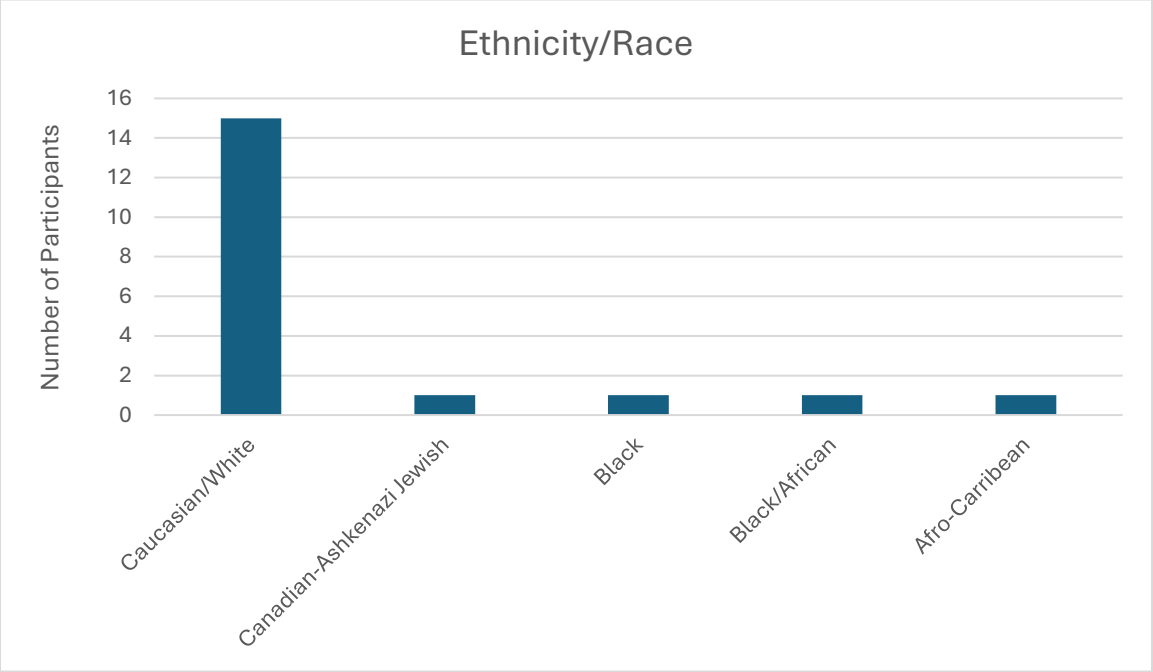
Twenty participants answered this question. Most of the participants were female (n=17) and (n=3) were male.



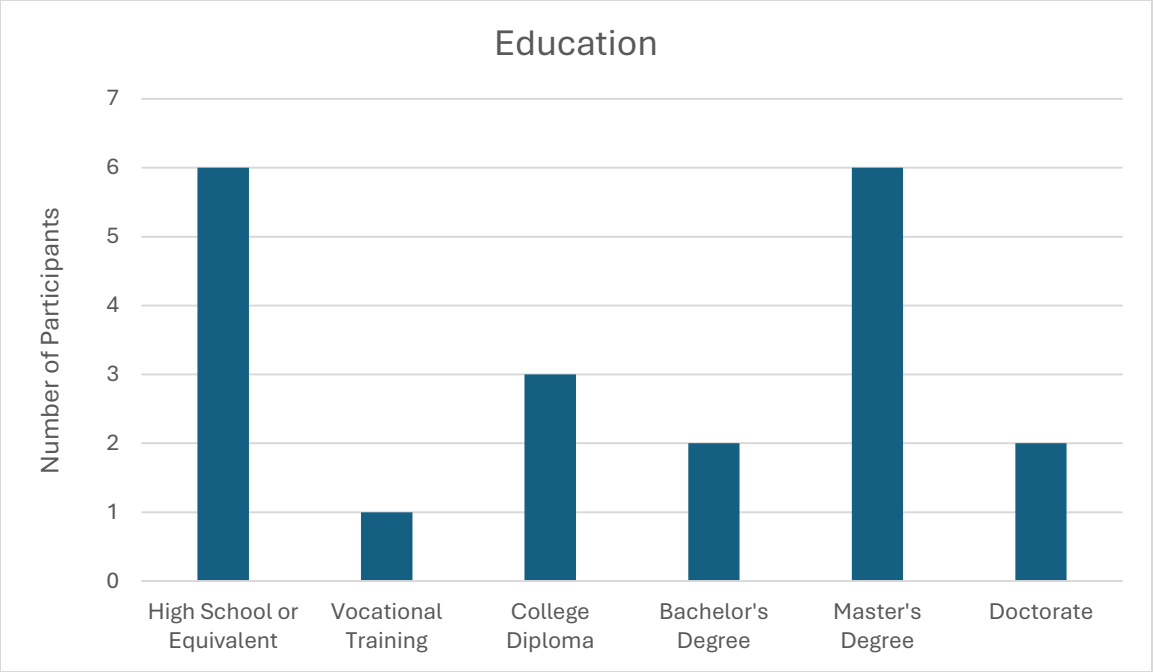
Eighteen participants answered this question. Most participants' gender identity aligned with their sex (n=17) and (n=1) identified as non-binary.



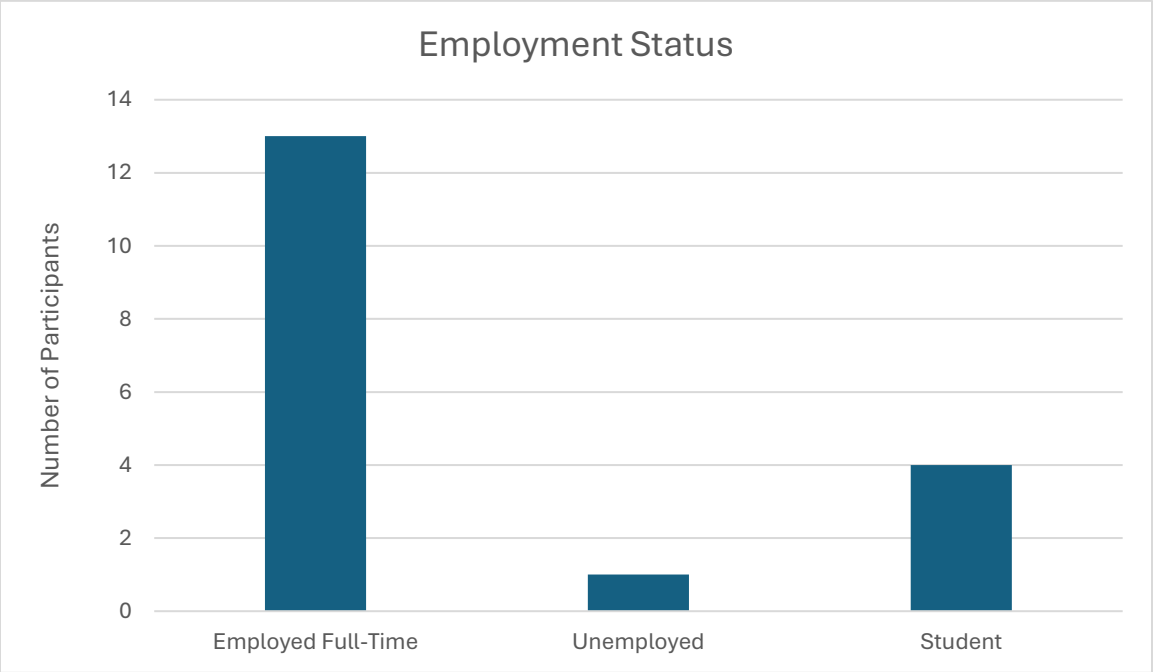
Eighteen participants answered this question. Most participants had a heterosexual or straight sexual orientation (n=14).



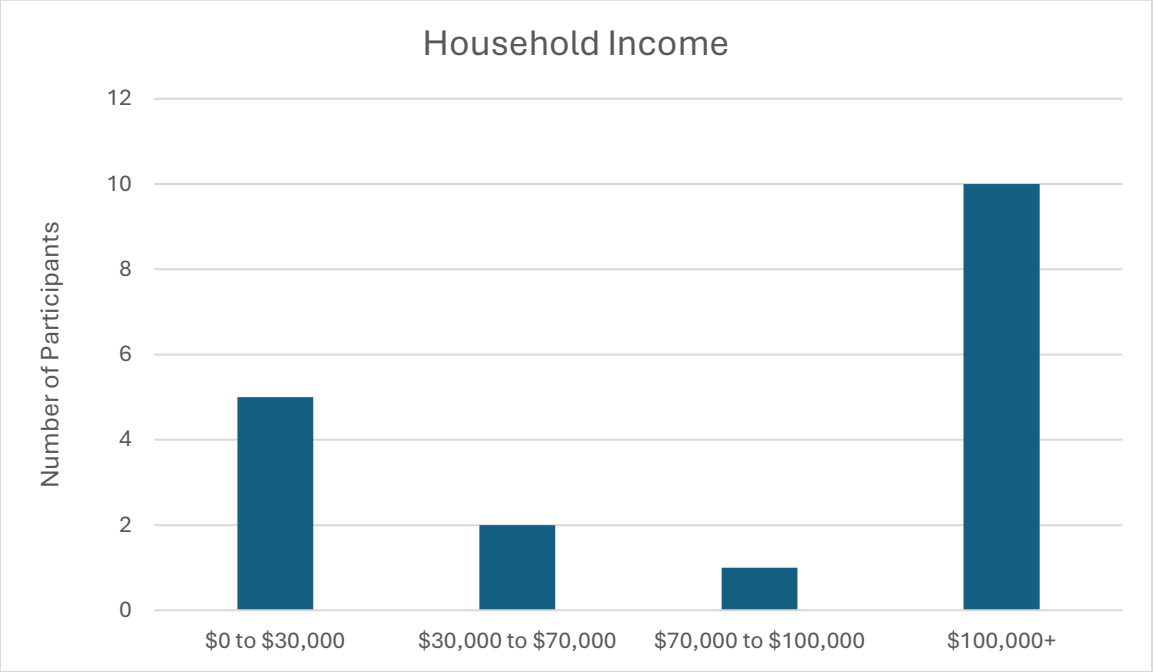
Nineteen participants answered this question. Most participants identified as Caucasian/White (n=16).



Twenty participants answered this question. The highest level of education achieved by the greatest number of participants was high school or equivalent (n=6) and master's degree (n=6). This could be due to the fact that many participants were recruited through universities and were completing either undergraduate or graduate studies.



Eighteen participants answered this question. Most participants were employed (n=13).



Eighteen participants answered this question. Most participants had a household income of $100,000+ (n=10).

Most of the participants were female, heterosexual, Caucasian, university educated, employed, and with a household income of $100,000+. This could be due to the fact that the most successful recruitment strategies were recruiting through universities and mental health organizations. Participants might also be living in multi-income households. This research study was not funded and compensation could not be provided to participants which likely disincentivized individuals outside of universities and mental health organizations from participating in the research study. The socio-economic factors that participants specifically highlighted as affecting their experiences were ethnicity/race, education, employment, and age. The study does not include a large number of racialized participants, but their responses have been highlighted in the interview section when their ethnicity/race affected their experiences.

The research study does not include a large number of participants who do advocacy work outside of academia or mental health organizations so the results might not resonate with mental health service user advocates who do advocacy work outside of those sectors.

5.3 Interview Findings

All twenty participants completed the interview over Zoom. The interview guide can be found in Appendix C.

5.3.1 Advocacy Journey: Origins and Motivations

This section highlights that participants started their advocacy journey because of the types of activities they were engaged in. It also discusses what motivated participants to start their advocacy journey, and that lived experience influenced their decision to do advocacy work. Details of the type of advocacy work they were engaged in is described in section 5.3.2.

5.3.1.1 Origin

Participants shared that they were empowered to engage in advocacy work through school, employment, and volunteering. Participants who were enrolled in postsecondary education were studying social work, psychology, health, or Mad Studies. These fields of study tend to be critical and include discussions about mental health. Participant 11 said “The university definitely played a big role in empowering me to get involved in advocacy”. Participant 1 said “Education was, I think, critical to encouraging me to formulate my own resistant ideas to the status quo of this idea of mental illness”.

Participants were also able to do advocacy work because they were employed at organizations that do advocacy work, and it was a part of their role to do that work. However, the types of advocacy work participants were engaged in could be limited due to the work they were

doing and the mandate of the organization. Participant 9 said “I'm empowered to do advocacy work by virtue of being part of an advocacy organization whose mandate is to do systemic advocacy”. Some participants said their employment was not directly related to advocacy, but their employment did help them start their advocacy journey. Participant 19 said:

> “So I held many different roles in the organization. Were they specifically related to advocacy through that whole time, probably not specifically related. But the whole idea of peer support and the importance of understanding how people with lived experience are able to support each other, kind of made me enter into more of that advocacy work.”

Participants started their advocacy journey through volunteering as well. Participant 3 said “I did volunteer work for five years. I spoke at jails and treatment centers and detoxes for five years. That's when I realized I need to do this full time”. Activism allowed participants the freedom to do the advocacy work they wanted to do and to develop a more critical perspective on mental healthcare. Participant 5 said:

> “I was engaging in activist circles, I was sharing my story, which is a typical form of lived experience engagement, I began to get connected with other activists who had different points of view and different understandings of mental distress, neuro divergence that hadn't been presented to me, and I think that really evolved my understanding of my experience and the service that I'd been given”.

5.3.1.2 Motivation

Participants were motivated to engage in advocacy work by their desire to help others, desire to address problems in the system, and their privilege. Participants wanted to help others the way they had been helped, give back to the community, and help those in need. Participant 2 said “I do want to give back and help other people that are going through something similar to what I was going through. I kind of owe something to give back to the community.”

Participants were motivated to engage in advocacy work by their desire to address problems in the system. Participant 11 said:

> "I also realized that there were gaps in the system. For example, long wait times, lack of clear communication about what services were available, and not enough options for students who needed different kinds of support. I did feel like the system could be so much better, and that feeling pushed me to not just accept it, but to try and do something about it".

Participant 20 said "I knew I wanted to do something in the field to try to make that whole system just slightly less crappy than it was".

A few participants said that they were motivated to participate in advocacy work because they knew they had a level of privilege that other people experiencing mental distress may not have. Their privilege was related to their ethnicity/race, level of education, and employment. Participant 20 said:

> "Another reason why I do advocacy work is because of my position of privilege. I know I was awarded a lot of privileges that not everybody gets in life. I do feel some responsibility to use that for good. To use that to try to advocate for change, for people that deserve some of the same opportunities that I've gotten".

5.3.1.3 Lived Experience

Almost all participants said that their own lived experience empowered them to do advocacy work. All participants had lived experience as mental health service users, and some participants also had family members who had mental health challenges. Participant 17 said "I have had mental health struggles for a really long time. I remember it starting more than, like, grade three, kind of I guess around there maybe grade four, and my mom had mental health struggles as well".

A few participants argued that they were not empowered to do advocacy work. Participant 7 said "I don't know if I would use the term empowered. Empowered sort of implies that there are mechanisms that I was able to find to support me when it's really just an initiative I took." Participant 8 said:

> "I don't know if I necessarily feel empowered working in these systems, because I don't feel like I have any power. If anything, I feel more disenfranchised and like even more disempowered than ever in these systems. The more I get into it, the more I realize that I have less and less power to make these changes…I have more power when I've created spaces for myself to do this work, versus actually working within these systems of government".

Participants discussed how a sense of community and the community they belonged to empowered them to do advocacy work. People in their community gave them the strength and inspiration to do advocacy work. Participant 6 said:

> "I met a lot of folks who were working in the community, most of whom identified as psychiatric survivors, who were doing community advocacy work. That changed my life. That opening up of seeing people that you love and admire, doing resistant advocacy work and speaking oftentimes directly against folks in the disciplines who are supposed to help them".

Participant 18 who was a Black/African Muslim female student said:

> "People who look like me need to speak for others, in terms of advocacy, and also just kind of being able to relate to them, sharing similar backgrounds and experiences. So that's why I think it's important, and I feel like I've been a voice for these people."

In summary, participants started their advocacy journey through school, employment, and volunteering. They were motivated to do advocacy work by their desire to help others. They were also motivated by their desire to address problems in the system such as long wait times, people not being informed about the services that are available, and there not being enough services available. Participants were also motivated to do advocacy work by their belief that they had a level of privilege that other people do not have. Participants' lived experience with mental health challenges and the communities they belonged to influenced their decision to do advocacy work. A few participants felt they were not empowered to do advocacy work because they needed to take initiative and create spaces to do advocacy work themselves. They did not receive support and mentorship to start their advocacy work.

5.3.2 Nature of Advocacy Work

This section outlines the type of advocacy work participants are engaged in to improve mental healthcare and policy in Ontario. Participants' advocacy work was related to education, peer support, fostering collaboration, changing policies, and changing laws.

5.3.2.1 Education

Many of the participants did advocacy through education, research, and writing since these activities allow participants to control how knowledge is created and shared. Participants provided education on mental health through their work as university professors and created training and educational materials that addressed mental health challenges. Participant 7 said:

> "I'm also a professor in continuing education in the business and marketing programs. I've done a webinar there, and we'll be doing another webinar on creating safe workplaces, especially well, predominantly around mental health. So really, just educating and advocating people to understand how common mental illness and mental health challenges are on the whole. You know, really trying to educate them on the difference between mental illness and mental health".

Other participants spoke to government officials about issues in the mental healthcare system, raised awareness about mental health issues and supports within their communities, spoke about their mental health journey, and spoke about mental health on social media. Participant 16 said:

> "I was invited to speak at a provincial mental health roundtable in our community, which involved our local MPP and Associate Minister of Mental Health. I gave a speech which involved our journey through the mental health system within our area, our community, and how I felt that failed our daughter in providing additional help for what she was going through. The result of that meeting was that the Minister through his Senior Policy Advisor, later on that evening, as we met again, came to our table and said they would like us to have a youth wellness hub for our community".

Participants shared their writing on student forums, social media, news outlets, newsletters, and through guidelines for people working with individuals experiencing mental distress. Participant 11 said:

> “My advocacy journey began when I started sharing my thoughts in student forums on campus. Speaking about how mental health services could improve. At first I focused on things like the wait times for therapy appointments and the lack of awareness around the resources available”.

Participant 7 said “I have a reasonably public platform, not like an influencer or anything like that, but like a reasonably public platform in the financial services sector. I'm interviewed oftentimes for periodicals”.

A couple of participants were part of research projects related to mental health and housing. Participant 5 said “I became a lived experience co-investigator on a project examining adolescent experiences of recovery, like that personal recovery phenomenon that I mentioned, and I leveraged my lived experiences there to connect with youth in this project.” Participant 1 said “I was part of a large research demonstration project that was trying to provide an evidence base for the value of the housing first program model.”

5.3.2.2 Peer Support

Some participants did advocacy through peer support work which allows them to use their lived experience to help other individuals who experienced mental health challenges. Participants helped develop peer support initiatives and infrastructure, ran peer support groups, provided peer support to individuals and advocated on their behalf, and advocated for more peer support services and funding. Participant 18 who was a Black/African Muslim female said:

> “I used to run like a peer support group, like through the mosque. It's through word of mouth, and I've had, you know, several people from the community reach out to me and talk to me about their struggles. I've just kind of offered like, more peer support based assistance”.

Participants also advocated for more peer support employment opportunities so that people with lived experience could positively contribute to the mental healthcare system and provide care for others. Participant 20 said:

> “I've done a lot of advocacy work for the field of peer support. Trying to create employment opportunities and professional development opportunities for people with lived and living experiences of mental health challenges. Making sure that those people have the opportunity to contribute to the mental health system and provide care to others”.

A few participants advocated on behalf of their clients, friends, and family to ensure their needs were met. Participant 12 said:

> “I work in a government agency, and I'm a frontline provider. So a lot of the policies are set, and that's not where I'm advocating. It's at the level of the user, or to stretch the timelines of program applicability, or something like that. That's where I'm advocating for a client that's actually in need of service that they can't access in any other way”.

Participants believed that advocacy does not need to be formal and can be as simple as making a positive impact on the people in your life. Participant 17 said “I advocate for like friends and family who I guess are experiencing troubles”.

5.3.2.3 Collaboration, Policy, and Law

Some of the participants’ advocacy efforts were focused on increasing collaboration across sectors and professionals that are trying to work with people with mental health challenges to improve the mental healthcare system. They tried to increase collaboration across agencies, with government officials, created regional networks, and a mobile crisis response team that involved police, nurses, social workers, and civilians. Participants were also involved in advocacy groups such as Child and Adolescent Mental Health and Addiction group, Mental Health Awareness Group, Black Student Association, and a Diversity, Equity, and Inclusion roundtable. Participant 16 said:

> “What we did in that case was to work at bringing all these different agencies together, that because their main challenge was that they're all silent, and so much of this meeting where a lot of them didn't even know each other, because they operated in the world, and there's no collusion between them, and there's no cooperation between them in a lot of cases. We're redesigning how that system works, so there is that cooperation among inter agencies. The biggest development that we're working on and having success on is to use a common database between these agencies”.

Some of the participants focused on changing and improving policies and laws. Participants tried to improve organizational policies to protect human rights, increase cultural competence, increase the ability of clients to advocate for themselves, and consider the lived experience of people experiencing mental health challenges. Participants also tried to improve policies at the provincial level and create a more holistic approach to mental health. Participant 20 said:

> "We try to create policy changes and stuff like that, that consider the lived experience perspective more. I try to make sure that when we're making decisions about how we spend money, how we design programs, how we write program policies, all of that kind of stuff, that we're actually thinking about the people that are impacted the most, as in the service users".

In summary, participant advocacy work focused on education, writing, and research in order to raise awareness about mental health issues. Participants also focused on peer support so that people with lived experience could help others that faced similar challenges. Participants advocated on behalf of their clients, family, and friends to ensure they had access to the support and services they needed. Participants also worked on fostering better collaboration across sectors and professionals to improve mental healthcare services. Participants worked on changing policies and laws to ensure that the voices of people with lived experience are heard and that they are protected.

5.3.3 Challenges Faced

Participants described many different types of challenges they experienced while doing advocacy work. There were personal challenges, systemic challenges, and challenges related to theoretical lenses and assumptions.

5.3.3.1 Personal Challenges

Participants shared that they experienced vicarious trauma while doing advocacy work. Participants experienced vicarious trauma when they heard about clients being physically and chemically restrained and when they learned about clients' trauma and suffering. Participants said client stories would remind them of their own trauma, trigger them, and make it hard for them to remain strong. Participant 2 said:

> "If they have to restrain someone physically, then that has to be reported to their Board of Directors. So there was an incident that was hard to hear because I have been restrained in the hospital setting, physically and chemically. So it was triggering to hear".

Participant 3 said "It can be challenging, trying to remain strong with some of the horrific stories that I hear, that they've suffered in their life".

Participants experienced negative impacts on their mental health such as feeling pressured, anxious, drained, frustrated, uncomfortable, and having days where they could not get out of bed or continue to work. Participant 7 said "There are days I do not get out of bed. If I'm lucky enough to work that day, I will work from my bed, because it's just too hard to face the world". Participants were worried about being judged, stigmatized, and losing relationships. Participant 11 said:

> "I was just constantly worried about being judged or, like, seen as weak or overly emotional being a girl as well. It was hard enough dealing with mental health challenges privately, but when you put yourself in the position to advocate for others, the fear of vulnerability and judgment becomes a lot heavier".

A couple of participants felt there was a target on their back and received backlash about what they shared on social media. Participant 8 who was an Afro-Caribbean female said:

> "So personal challenges is definitely recognizing that if this is something you're going to do and you want to actually implement change, you're really putting like a target on your back, especially as a racialized person. It is not easy work. It is stigmatizing to yourself in terms of like, now there is a target on your back. Like people are going to scrutinize the work you do. They're going to criticize the work you do. Some personal challenges are

> even losing certain friendships and people around me that I thought understood the scope of work and the importance of that work".

Participants experienced issues in their professional lives because of the advocacy work they were doing. Participants were concerned that they would be seen as a liability and that they would be denied employment opportunities. Participant 7 said:

> "There was a lot of perceived risks for me. What if my employer took that to mean I wasn't able to do my job? What if potential future employers or people that would want to work with me or collaborate with me saw me as a liability right now".

Participants had difficulty balancing the needs of the organization with the needs of the clients, they had a hard time being objective given their own lived experiences, and they had to remain professional while experiencing vicarious trauma. Participant 2 said:

> "My role is to provide the best advice to the organization. It's not to look out for the clients, but it's really to look out for the organization as a whole. So it's hard to wear that hat and put my own personal experience aside and think objectively".

5.3.3.2 Systemic Challenges

A systemic challenge participants experienced was related to government changes and bureaucracy. Participants said it takes a long time for government agencies to change policies, there is a lot of red tape and bureaucracy which prevents people from getting the help they need, and it feels like you need to start all over again when government changes happen. Participant 19 said:

> "The systemic challenge, I would probably say, is the government changing every time. Every time you think you're getting somewhere, and then there's a change in the government, whether it be an actual change in the government, or staff changes, or minister changes. Every time you feel like it's one step forward and you're making a difference, and people are starting to understand what it is that you'll do, and what you're advocating for, then you know, there's a change, and you lose that work".

Participant 4 said:

> "There is a lot of bureaucratic red tape and anything, you know, it's do this and then do this, and then apply this, and then go on this list. Meantime, I'm trying to help people

now. I'm really doing this stuff at a street level. These people don't really have the luxury of waiting around for somebody to listen to them".

Participants were frustrated by what was not being prioritized and funded. Disability and human rights are not prioritized, critical interpretations of mental health are not a priority, trying to find the latest gene is prioritized over housing, and there are competing agendas and priorities which prevent universal messaging. Participant 9 said:

> "There is a lack of prioritization of human rights. It's not that they don't do social determinants of health research, but it's like, what is the breakdown of allocation of resources and funding for those things. Particularly when the interests of service users, people with psychiatric disabilities, etc, might otherwise be different. People are probably more interested in housing than they are in finding the latest gene that will supposedly provide an answer to psychiatric disability. So who decides what the agenda for these things is, I think, a very politicized issue, and it's also an issue we bump up against in terms of doing advocacy".

Participants said decisions are made based on power, wealth, privilege, appearances, and politics rather than what is good for everybody even when what is good for everyone is backed by evidence and cost savings. Participant 20 said:

> "One of the hardest parts of it is doing it in a day and age where the rest of the world does not seem to be listening to reason. I think the hardest part is trying to do this work when it often feels like an uphill battle. It often feels as though, no matter how many facts, figures, data, you know, evidence-based research, we're able to offer decision makers, the decisions that they're making are not usually influenced by that kind of stuff. It's influenced by wealth and privilege and positionality and politics and looks and appearances and stuff like that, as opposed to being based on what's good for everybody".

A participant said the knowledge of professionals is given more authority and credibility than the knowledge of people with lived experience. Participant 5 said:

> "I think the advocacy work I do is really about situating people with lived experience as equitable partners. The psychiatric system and academia are two systems that are so inherently hierarchical in nature that working equitably within them is very challenging. Especially when we're thinking about epistemic injustices. That professional knowing is privileged and ways of knowing through lived experience is marginalized. So we bump up against those attitudinal barriers. They're also structural in terms of compensation, precarious employment, like all of these different things".

Funding was another systemic challenge that participants identified. Participants said it is difficult to criticize the government when you depend on government funding, it is difficult to allocate time to advocacy when the focus is on securing resources, lack of funding leads to understaffing, funding can be fragmented and funders have different aims, funding can be for very specific issues which limits the issues that can be worked on, and the right political buzzwords need to be used in order to secure funded. Participant 2 said:

> "Working with the funding partners is hard. There are a lot of requirements that they have. As an organization, we have to keep a very clean media image. Someone could bring some kind of story, which could mean that some of our funding gets pulled. So yeah, it's like you really want to keep a squeaky clean image, so you never want to be seen as critical of government".

Participant 20 said:

> "I have a responsibility to sort of keep this ship afloat and to make sure that our organization has the resources it needs to be able to support itself. That on its own takes, like, a huge amount of time and effort and energy and resources to just to sort of stay afloat. So then capacity left over to be able to allocate resources towards things like advocacy and setting policy tables and stuff like that, it's just not there because we spend so much time just trying to maintain our existence".

Participants felt frustrated when there was a lack of understanding about important issues and when decision makers do not understand the urgency of the issues people are facing. Participant 8 said:

> "Leadership is one of my biggest problems. Most of the folks that I've engaged with, at least, I want to say 90% and I'm being very nice, don't understand what it would take to actually make changes in mental health care, as well as policy to actually be transformative and actually to somewhat even reimagine what health care could look like in terms of actually supporting people".

Participants said it was difficult not to feel discouraged due to the lack of progress in improving mental healthcare and policy. They questioned whether or not they were making an impact or if their efforts were going unnoticed, it was difficult to challenge the status quo, there is a lot of talk but no action, they needed to keep repeating the same message over and over

again, and it was exhausting to put in the work and not know if it will result in lasting change. Participant 6 said:

> "The work is hard because there's not a lot of excesses. It feels like we're losing more than we are winning sometimes. That might be a problem of now, just given the policy environment that we're living in currently. It just feels really hard sometimes. So it's hard not to feel disenchanted. It's hard to keep going when you don't see so many wins".

Some participants said it was difficult to meet client needs because of challenges associated with the clients. Participant 3 said "Some of them have no doctor, some of them have no dentist. These were street entrenched people, and so their mental health and their physical needs were not met, because they didn't care at the time".

5.3.3.3 Theoretical Lens and Assumptions

Participants were not explicitly asked about problematic theoretical lenses or assumptions, but this information was discussed by participants. Participants stated that mental healthcare is biomedical and paternalistic. Participant 1 said:

> "We are all coming from very different epistemic points. I found the most difficult thing about doing advocacy work was that I was speaking around social justice, but it was being heard by most people through biomedical mental illness, chemical imbalance issues. We all think it's the same mental health and you're using language that you think they hear and understand. But they're interpreting what you're saying in a very dominant biomedical way. It can be extremely, not only frustrating, but also in some ways, stigmatizing, for lack of a better word".

Participant 5 said:

> "I have this tension about working in the system to influence change and promote equity. The psychiatric system is founded on the like, it's very paternalistic. It's founded on constructions of people as ill. If people weren't considered mentally ill, psychiatry wouldn't exist".

Another challenge with advocacy work is that actions are performative. Participants said there is so much performative action within mental health and policy that it makes it extremely challenging to move and shift things. Participant 8 said:

> “I think the systemic challenges are performative action, performative behavior. How can we continue to be colonial but not be too colonial at the same time? How can we appease the people who are complaining but still oppress them? Just to kind of, like, shut them up. It's like, you know, when a baby's crying, you give them their pacifier”.

Participants also commented on tokenism. They said there is a lot of tokenism around lived experience since only one person with lived experience will be part of a group working on serving people with lived experience. Even if someone has lived experience, they cannot speak for everyone who has lived experience. Organizations need to connect with more people with lived experience and not assume that talking to one person will help them understand what all people with lived experience want or need. Participant 18 said:

> “There's still so much tokenism around lived experience. I'm sitting on a working group and realize that all the people on this working group, and they're talking about how to serve people with lived experience, and there's not really other than myself, anyone with lived experience on this committee”.

Participants commented on how mental illness stigma created challenges for their advocacy work. Participant 16 said “What everybody has to recognize is that the issues behind the stigma in mental health and especially suicide are so strong that that's probably our biggest obstacles”. There are also assumptions made about people who struggle with their mental health. People assume that mental health challenges are not a normal part of the human psyche, that people have mental health issues because of the choices they make, and people make assumptions about what someone with mental illness looks like. Participant 14 said:

> “Actually once my hair turned gray during that time, I kind of thought maybe I'm too old for this. But then I thought, well, mental illness goes across all strata of ages and cultures. So I thought, well, they might need an older person to be a speaker and they could relate to me being older”.

In summary, the personal challenges participants experienced were vicarious trauma, negative impacts on their mental health, backlash from others, and professional issues. The systemic challenges participants experienced included government changes and bureaucracy,

priorities, what decisions are based on, epistemic injustice, funding, lack of understanding of important issues, lack of progress in improving mental healthcare and policy, and clients creating issues. The biomedical and paternalistic theoretical lens of mental healthcare and policy was also a challenge. Other challenges included performative action, tokenism, and stigma.

5.3.4 Key Facilitators and Enablers

This section outlines the facilitators and enablers for advocacy work which include funding, community, and personal factors. It discusses how the current system can make advocacy work easier to do and how people can personally make advocacy work easier to do.

5.4.5.1 Funding

Participants said that receiving funding makes advocacy work easier to do. Participants said it was helpful when they had pilot project funding, when the organizations they were working at received continuous funding, when funding allowed them to hire more staff, and when there was a budget line allocated to engaging people with lived experience. Participant 5 said "I think, also having budget. Writing it into strategic directions, like lived experience engagement in strategic directions. Backing that up with a line in the budget for it is essential if you actually want to do this well".

5.3.4.2 Community

Participants said community, collaboration, and social media helped them do their advocacy work. Participants mentioned that community is helpful because people inspire them and make them want to continue their advocacy work, they receive support, they have collective power, they engage with diverse people with different perspectives, they are able to build spaces to have open and critical conversations, they build relationships, and they are able to connect with people who are impacted by the issues. Participant 8 said:

> “One of the greatest facilitators is the opportunity to engage. Having that openness in terms of that engagement. Working with people and having those spaces to have conversations and be critical. Come up with action plans and do that work and learn from each other. So I think that, in itself, personally, is like the advice that I give to everyone is just that openness of like, community. I don't think there's anything stronger than community most of the time”.

Collaboration also enables participants to do advocacy work because they need other people’s power, support, resources, and networks to make required changes. Participants collaborated with government officials, agency leaders, frontline workers, clients, and management. Participant 5 said:

> “I think it happens in collaboration. I think it requires power sharing. I think for those who are situated in positions of power, it requires allyship, compassionate leadership, and using their position to facilitate spaces where, like, shared decision making and shared accountability can occur”.

Participants were grateful for the support they received from others because it allowed them to do their advocacy work more effectively. Participant 11 said:

> “I also found that having faculty members and staff who are generally interested in mental health made a huge difference. Some professors and administrators have been incredibly supportive, and it felt like they really listened and were open to making changes”.

A participant said that their advocacy efforts were successful because they were not trying to make the changes themselves but that they were able to convince people who could make the changes to do so. Another participant said that it is important to have reciprocal relationships with people where you support them and they will support you in return.

A couple of participants said that social media provided a platform for them to amplify their voices, talk about mental health, spread information about supports, and reach a larger audience. Participant 11 said:

> “Social media also has been a big help, too. It's a space where we can amplify our voices, like making posters talking about mental health. If you need anyone to talk to, there's like, a group meeting we're holding every, for example, Thursday at 4pm like that. It

> actually encouraged people to come together and talk about their issues and everything. So it really made it easier getting our message out to a larger audience through social media, especially".

5.3.4.3 Personal Factors

Participants discussed how personal factors and lived experience helped them in their advocacy work. Personal factors included professional communication skills, personality, their position, their willingness to do the work and take initiative, their privilege, and their faith. Participant 7 said:

> "It's a mindset, and so you have to be able to personally, just ignore that. It's just noise, it's white noise, it's their opinions. They're entitled to them. They can do what they want with them, but you can't let it derail you. So personality is kind of a big one in advocacy. I don't say thick skinned, because I hurt too when I get some of the negativity. But just understanding that it's perspective. It's their life journey that they've been through. Right? We can only do what we can with what we know".

Participants argued that lived experience is a powerful factor for engaging in advocacy work. People with lived experience can relate to the people they are advocating for, they have insight into what people need, and they have personal experience with the system and problems. People with lived experience should also be paid and included in governance structures. Participant 16 said:

> "I mean what seems to be so powerful in our community and our world today is people with lived experience. I've been told that a number of times that people with lived experience can create far greater change than other people. Once you have lived experience, people can relate a face to an actual person that's more meaningful".

In summary, participants stated that funding enables them to do advocacy work because it provides the resources they need to engage in that work. Community, collaboration, and social media act as facilitators for advocacy work. The communities participants belong to are able to support them, give them a space to discuss important issues and learn from each other, and gives them collective power to take action. Collaboration allowed participants to work with people

who could enact positive changes. Social media allowed participants to amplify their voices and reach a large audience. Personal factors allowed participants to persevere in their advocacy efforts. Lived experience was also a facilitator and enabler for advocacy work because they had personal knowledge of the issues and were able to provide effective solutions based on their experiences.

5.3.5 Personal and Collective Rewards

This section outlines the rewards of doing advocacy work which include personal benefits, finding meaning in difficult experiences, finding community, seeing positive changes, and helping others.

5.3.5.1 Personal Benefits

Participants said they received personal benefits from doing advocacy work such as feeling satisfied, feeling reconnected to their true self, fulfilled, appreciated, empowered, less alone, free, and a sense of accomplishment. Participant 11 said:

> "I also gained a lot of personal growth. I became a lot more confident in speaking out in public, to navigate difficult situations and work with people that have different perspectives on different things. It also opened up my eyes to a wider systematic issue that affects how people experience care, and it's been empowering to contribute to that conversation, to be honest".

Participants also received recognition for their work, awards, and payment. Participant 8 said "Accolades are always great. It's always great to get recognized or to get an award or get money or something for this work".

5.3.5.2 Meaning and Community

Participants said that their advocacy work helped them find meaning in their difficult experiences and a sense of purpose. Participant 2 said:

> “It kind of makes it feel like what I went through wasn't for nothing. Like, yeah, it was really, really difficult, but at least I survived. If I can use what I went through to help other people, then it's easier to accept what happened to me”.

A few participants said that they benefited from their advocacy work because it helped them become a part of the advocacy community. Participant 6 said:

> “I think it's important to think about this work as a movement. It's not something we do on our own, or, I mean, I hope it's not something that we do on our own. That we act in community, we act as a collective, as a movement. So that, to me, feels like a benefit. I feel good about that. I feel good about acting in collaboration, in a collective”.

5.3.5.3 Positive Changes

Participants said that the rewards of their advocacy work were the positive changes they were able to make. Positive changes included creating change in the community, ensuring the voices of service users are heard, improvements to best practices, changing people’s minds about an important issue, meeting the needs of clients, saving lives, and more peer support work opportunities. Participant 20 said:

> “Seeing that people have been awarded opportunities to work in the field of peer support because of some of the advocacy we've been able to do. That's a big motivating factor. To be able to see that somebody with schizophrenia got access to peer support training, and now they provide peer support services at the Schizophrenia Society. That's a very motivating sort of thing to witness”.

5.3.5.4 Helping Others

Participants said that their ability to help others with their advocacy work was rewarding. Participant 18 said:

> “Just going through my own struggles in life and helping someone make their day a little bit better, or just even having them gain the skill sets to develop better habits, or develop better coping strategies and dealing with life. I think that is immeasurable”.

Participant 17 said “I need to be the person that I needed as a kid kind of thing. So I guess it kind of gives like personal comfort knowing that I could help someone else”.

In summary, the rewards of advocacy work were the personal benefits participants received such as positive feelings, growth, and recognition. Participants were able to find meaning in challenging experiences and used their experiences to help others. They were also able to find community with other people who had similar experiences to them. Seeing that their advocacy work resulted in positive changes and that their advocacy efforts were effective was rewarding. It was also rewarding to help others who were struggling with mental health challenges.

5.3.6 Impacts on Policy, Mental Healthcare, and Community

This section outlines the impact participant advocacy work has made on mental healthcare and policy. Participants' advocacy work has made impacts through policy change, service creation, organizational change, awareness raising, and by helping others.

5.3.6.1 Policy

Participant advocacy work led to changes in organizational policies, regulations, the creation of an open-door policy, and a policy related to the use of restraints on clients was changed. Participant 9 said "We've been involved in inquests, and one of those inquests had to do with the use of restraints. So that changed the policy on restraints". Participant 7 said:

> "All of our team has open door policies. Meaning it doesn't matter who you are, you could seek out anybody from your direct manager all the way up to myself. They know they can email or call me or send me a message on teams, and they know it's an open-door policy. Let's talk about it. Let me get some resources in front of you. If it's outside of my realm of influence, let's get you supported moving forward".

5.3.6.2 Service Creation

New services were created such as a youth wellness hub, legal clinic, peer support services, civilian led crisis response team, and a recovery community center. Participant 20 said:

> “There's been a huge sort of, I call it like a glow up of peer support. A big increase in and use of peer support. An increase in recognition for the value of peer support. So I think in Ontario, it's officially now been, sort of stated that peer support is part of the core service framework for Ontario. So there's been concerted efforts to make sure that people accessing mental health services do have access to peer support services”.

Participant 3 said “The recovery community center. We in the last couple of years have had different organizations that go for tours to come through to see the model that we've created and hopefully to duplicate it”.

5.3.6.3 Organizational Change

Organizational changes included changing practices, including equity and diversity measures on the board level, implementing a patient bill of rights, and people with lived experience co-producing strategic directions. Participant 9 said:

> “We've been able to get the hospital to change their practices and some of their policies. There's, of course, the bill of rights, which is an example of fighting for and then getting a patient bill of rights. Now that's available to any patient who comes in the hospital. That becomes important because it gives people information about what's happening to them when they're in the hospital and what their rights are”.

Organizations also improved communication about available mental health services, offered more therapy appointments, offered more virtual mental health services, allowed for more personal emergency leave days without any questions asked, and provided extra resources for crisis management. Participant 11 said:

> “The university actually improved its communication around available mental health services. They were sending out more emails to people. There's group therapy sessions that if you're available, just click the link and join. We also saw an increase in the number of therapy appointments available and push towards offering more virtual services”.

5.3.6.4 Raising Awareness

Participants were also able to raise awareness about different perspectives on disability and justice, Mad Studies politics, peer support work, and how to work with people with lived experience to meet their needs and improve the system. Participant 5 said “I've been invited to be

a lived experience advisor on tables at various healthcare organizations. I'm advising health system leaders in terms of their system, the system planning, and responding to community identified needs". Participant 9 said:

> "I personally have done a lot of work with psychiatry residents and trying to educate them around disability politics and Mad Studies politics. I wouldn't say that's had a huge like, they don't change their behavior, but it's a way of introducing curriculum into a taboo space".

Education about disability justice and Mad Studies can lead to systemic change by challenging dominant biomedical narratives and exposing healthcare professionals to new ways of thinking about mental health which could influence their practice.

5.3.6.5 Helping Others

Participants' advocacy work had a positive impact on others including representing disabled people and service users at the Human Rights Tribunal, allowing clients to gain access to services, making people happy, giving people the confidence to speak for themselves, and helping people achieve their goals. Participant 10 said:

> "With my people, huge, it's been life changing. I know, in layman's terms people have said my strength is what gave them strength or courage or power to make the changes they needed to in their lives. It's helped pull them out of stagnation".

Participant 18 said "One individual that I was working with after working with her for a little over a year, just on a personal basis through peer support, went back to school to pursue social work so that she could help others".

In summary, participant advocacy efforts led to policy changes which improved organizations, practices, and working environments. Participants were able to create services such as a youth wellness hub, legal clinic, peer support services, civilian led crisis response team, and a recovery community center that addressed the needs of people with mental health challenges. Organizational changes were implemented to include the voices of people with lived

experience of mental health challenges in decision making. Participants raised awareness about disability, justice, Mad Studies, and peer support. Participants helped the people in their lives and the clients they worked with.

5.3.7 Promising Approaches for Improving Mental Healthcare and Policy

This section discusses promising approaches for improving mental healthcare and policy. Participants were asked about promising approaches that would improve the mental healthcare system and promising approaches that would improve experiences for mental health service users.

5.3.7.1 Approaches Involving the Mental Healthcare System

Participants said that promising approaches for improving the mental healthcare system include increasing funding, increasing supports, and greater collaboration in the sector. Participants recommended increasing funding for education for people who work with mental health service users so that more services can be provided and wait lists can be shortened, professionals should be paid more for working with a greater number of clients, funding should be sustainable so that pilot projects can move forward, services should be more affordable, and mental healthcare should be covered by OHIP. Participant 8 said “It is important to make sure that a lot more people are thinking about sustainability. I think a lot of us are exhausted at the fact that we've done 1000 pilot pilots, but there's no actual funding moving forward”. Participants stated that changes in government and political agendas affect the funding for projects.

Participants said there should be more timely access to care, virtual mental health services, peer support, support for people with milder mental health challenges, affordable housing, and civilian crisis response teams. Participant 2 said:

> “Virtual care has really emerged from the pandemic as a viable option, especially for mental healthcare. So that's something that's just way more available nowadays to find a therapist to meet your needs. Like anywhere in the country, in the world, even, and, you know, getting the support you need even virtually. If you can't find somebody to provide that in person to you. I think that's a really promising thing”.

Participants also argued that there should be more collaboration across disciplines, between politicians and agencies that want to create change, between social workers and police, and between community-based agencies and hospitals or other institutions in order to provide better services. Participant 17 said “I think that there needs to be more social work involved in the policing system because a lot of calls that they make are related to issues that are potentially related to mental health”.

5.3.7.2 Approaches Involving Service Users

Participants said that we should include people with lived experience in decision-making, raise awareness about mental health issues, and reduce mental illness stigma. Participants said we should create a system that makes space for people with lived experience, knowledge and services should be co-produced, lived experience researchers should be part of research teams, and mental health service users should have more input into their treatment. Participant 5 said:

> “Creating a system that actually makes space for lived experience. Instead of asking people with lived experience to assimilate into the current psychiatric culture and associated academic structures. I think it's about creating space for people with lived experience to come and collaborate with people with professional expertise and co-produce the future together”.

Participants also discussed the importance of having frontline workers who represent the demographic they are working with and ensuring that people from diverse racial and ethnic backgrounds are more involved in their care. Participant 18 who was a Black/African Muslim female said:

> “I think having frontline workers that represent the demographics that they are aimed to help would be a really big step in just creating that environment where people who access

> these services have someone who looks like them. Who perhaps even speaks the same language as them. Especially with having a lot of immigrant populations coming to Canada wanting to access these services. You know, language is a big barrier. So when you don't have staff who speak a certain language, and then you have a population who is attempting to access these services, it is quite a big barrier, and it's going to put off people from wanting to seek help".

Raising awareness involves educating people about services that are available, encouraging them to reach out for help before they are in a crisis, normalizing the fact that everyone needs someone to talk to, and ensuring people are aware that medications are not the only treatment option. Participant 7 said:

> "But I think the user experience would be improved if they didn't feel marginalized. Like, if you're not in crisis, you're not really mentally ill. That's kind of the message we're sending right? If you don't want to kill yourself, you're fine, get over it, but that's not the case, you're just as important. Just because you don't want to die doesn't mean you're not struggling. Doesn't mean you don't need help. I think unfortunately, because we're so busy trying to help those in crisis, rightfully so, that there's this larger group that feels like they should just be okay".

Participants said we should reduce mental illness stigma so that it is easier for people to ask for help and we should get rid of the stereotype that people with mental illness are dangerous. Participant 4 said:

> "I think anything that will reduce stigma, you know, particularly mental health, there's still a lot. I think also then educating people, you know, this person that's talking to himself is not necessarily a danger to you at all. I think there's a lot of fear involved in it, both for the people that are suffering and the people that are seeing them in their own society".

In summary participants said the mental healthcare system could be improved if more funding was provided for education, staff, and mental health services. Participants also argued that the mental healthcare system could be improved if there were more supports for people with mental health challenges and more collaboration across the sector. Promising approaches for improving the mental health service user experience involves including people with lived experience in decision-making, ensuring the mental healthcare system addresses the unique

needs of people from diverse backgrounds, raising awareness about mental health issues, and reducing mental illness stigma.

5.3.8 Identifying Policy Mechanisms

This section discusses participant awareness of policy mechanisms that can be used to include the voices of people with lived experience. It also explores how policy mechanisms are framed and if such framing limits the policy process.

5.3.8.1 Mechanisms

Half of the participants were not aware of any policy mechanisms that can be used to include the voices of people with lived experience because they were not exposed to policy mechanisms in their advocacy work. Other participants said there are policies that require hospitals to include stakeholders such as patients and families in decision-making, organizations are implementing policies that require people with lived experience to be a part of decision-making processes, and there are advisory boards, committees, and councils that include people with lived experience. Participant 8 said “Within Ontario itself, they actually have stated that we need to be having ongoing engagement. Even advisory from communities and people with lived experiences or people who are service users of these actual services within all healthcare”. Some participants argued that there are opportunities to engage but they are not broadly advertised, and you need to seek them out yourself which can lead to the same people always being included in decisions. Participant 13 said:

> “People aren't aware. If they're looking for regular people, or people who, you know, engage in the system. I don't know how they transfer or share the knowledge. Sometimes it's always the same people who respond. It depends on who passes the information on”.

5.3.8.2 Feeling Unheard

Participants stated that even when people with lived experience are included in decision-making their opinions are not listened to, and their voices have been co-opted. Participant 20 said:

> "We need to do a better job at listening to those voices when they're there. Sometimes in clinical environments, like hospitals, for example, we have peer support workers working in those hospitals who are hired to provide their lived experience perspective. To try to shift the perspective and the way that we look at mental health. Sometimes those efforts are seen as being combative and ignorant and sort of outside the scope of their role. But that's literally the reason why we hire peer support workers".

Participant 9 said:

> "Now people do have, like voices at tables. I would say that what's happened is they're not political. I would say they're not politicized. I feel like a lot of those voices have been co-opted. I think inclusion has made people feel like they're included, but it doesn't actually change the system. One of the barriers to advocacy is the very issue of including service users more in a system that has taken people and made them an extension of their own agenda. I was just watching something before I got onto the call with you, and it had this service user speaking from that lived experience for the institution. I just thought that she's speaking about her personal story, which is fine, but kind of it's being tokenized and used in a particular way to make the hospital look benign and kind of harmless. I think she doesn't have an analysis of how she's being used in that video, but she feels good about being included in the video. More critical voices need to be included, and they need to be included as a collective".

5.3.8.3 Implementation

Participants said there are problems with the way policies are implemented. There are questions about how to apply international laws, there is variability in how people interpret criteria for accessing services, implementation is not always monitored and evaluated, and people interpret the language of policies in different ways which affects implementation.

Participant 6 said:

> "There are additional questions about the direct application of international law, including the Convention on the Rights of Persons with Disabilities into Canadian domestic law. So that's actually the subject of some really important litigation going on

> right now. How does it actually translate into an on the ground protection for service users? It's actually an ongoing legal question".

5.3.8.4 Framing

Participants said policies are framed in a biomedical and paternalistic way. Policies are framed in ways that are too clinical and technical which feels disconnected from the experiences of people, it reduces people to a diagnosis, and the only solution presented is medication which can be harmful. Participant 5 said:

> "It's very rooted in biomedical constructions of distress and neurodivergence, which is a very limited perspective. I think it limits the possibilities that we can see for the future of the system. I would say the policy that we have is insufficient right now because it's rooted in these assumptions of difference in biomedicalism".

The system is also paternalistic where people's autonomy is taken away and they can be forced to undergo harmful biomedical treatment. Participant 20 said:

> "A very paternalistic system where they were told, this is what's wrong with you take this medication and you'll be better or they were told you're unwell and you're never going to get any better. So they were locked up and treated horribly, and lobotomies and all that".

In summary, half of the participants were not aware of policy mechanisms to include people with lived experience in decision-making processes. The other half of the participants were aware of policy mechanisms that included engaging people with lived experience in decision-making processes. Participants argued that even when people with lived experience were included, their voices were not listened to because they were seen as combative, ignorant, or too radical. Their voices were depoliticized and used for other people's agendas. There are also issues with the ways policies are implemented because they can be interpreted in different ways. Policies are framed in biomedical and paternalistic ways which limits the policy process, our understanding of mental distress, and the supports provided to people experiencing mental distress.

5.3.9 Participant Recommendations on Advocacy

This section discusses the advice participants want to share with individuals who are interested in doing advocacy work to improve mental healthcare and policy in Ontario.

5.3.9.1 Recommendations for Advocacy Work

Participants shared that there are different ways to help, advocacy work is demanding, and progress takes time. There are different valuable ways to approach mental health advocacy and it is important to question your approach to advocacy. Participant 5 said:

> "Don't get stuck in thinking your approach to advocacy is the only approach. We can't turn on each other. I think that when things are this complex, we need to come at it from all angles. We don't all have to agree about the best approach to realizing these goals. There's value in kind of different approaches to advocacy and working in solidarity with each other rather than against".

Participant 1 said:

> "It's an ontological and epistemological question of like, how are you approaching mental health advocacy, like, what are you identifying as the problem? Because if your goal is to prevent madness, prevent these different ways of being in the world, then you are going to advocate for particular kinds of mental health policy and practice that other people would find violent or abusive and so on. Do you understand that there are a million different ways to think about depression as like an example? Are you making sure that you're not scripting your idea about depression and what works for you against everybody who experiences depression, because those are colonial logic. Those are racial logics. There are ways other than Western, biomedical ways of thinking about an experience".

A few participants wanted to warn people that advocacy work can be demanding. Participants said advocacy work is a fight that you are doing for free, it takes time away from your other priorities, you encounter a lot of resistance, it is challenging, it is hard, it is a lot of work, and it can be thankless. Participant 2 said:

> "Sometimes these advocacy roles are very demanding. I'm talking about a job in the field. They often don't pay well because they're done by nonprofits. The hours can be very long. You'll want to give your full self to it, so you'll work long hours willingly to do what needs to be done without being compensated for that. Without being acknowledged for that. So sometimes shockingly, like a mental health organization doesn't actually look

> after the mental health of its employees very well. All the staff are kind of in the same boat, like up to the CEO is probably stressed and not taking their vacation and, you know, working long hours".

Participants cautioned that progress takes time which can be frustrating and exhausting. Participants said to remember that you will be turned down, advocacy does not always work, and we should think of advocacy as a journey instead of a destination. Participant 12 said "Don't be discouraged if you face resistance or if things move more slowly than you'd like. Change takes time to be honest, and even small victories can make a big difference". Participant 11 said "Advocacy work can feel slow and frustrating because sometimes they won't listen. But every step forward actually counts, because you're doing something to help others and yourself as well".

5.3.9.2 Personal Recommendations

Participants encourage people who want to do advocacy work to practice self-care, have their voice heard, and build relationships. Participants said it is important to have your own mental health practices, do not burn yourself out, and it is okay to step back and forgive yourself when you are not able to do everything you want to do. Participant 2 said:

> "Just make sure you're looking after yourself. Not pushing it too hard to the point where you can't work or look after yourself like that isn't helping anyone. Have good work life boundaries. There are a lot of rights for people with mental health issues in the workplace. You can look into that and how you need to be accommodated. They should be happy to have someone with lived experience on the team and they also need to expect that that person's going to need time to recharge and look after themselves as well".

Participants said advocates should have their voices heard, speak out about injustices, communicate clearly about what the issues and solutions are, and get information to the right people who can make changes. Participant 12 said:

> "Find ways of getting information about who would benefit from the advocacy. Prepare it in a certain way and get it to the people that can actually make the changes. Plan that out

> from the beginning because I find that some advocacy work just doesn't get to the right people effectively".

Participant 13 said "So I think it's really important to share your opinions because if people don't speak out about injustice when it comes to mental health, disabilities, neurodiversity, nothing will change".

Participants stressed the importance of building relationships to do advocacy work effectively. Participants said advocacy work should be completed within a movement since we are stronger together, advocacy groups contain people with different skill sets that can be used to advance advocacy efforts, working with others helps you understand your experience within larger systems and structures, and you can take care of each other and get what you need. Participant 20 said:

> "Play nice. I think you kind of have to work with organizations and people to build relationships before you're really able to get some of your advocacy work done. I know there's different approaches to advocacy, but that's the one that's worked for me. Sort of building relationships and then using those relationships to try to find a collective message".

In summary, participants shared that there are different valuable ways to help and it is important to question your approach to advocacy. Participants warned that advocacy work can be demanding but it is worth doing. They also cautioned that progress takes time, but every small step forward is important. Participants recommended that individuals doing advocacy should take care of themselves to ensure that they are protecting their own mental health. It is also important to have your voice heard and speak out against injustices. Participants said advocacy is most effective when you build relationships with people who can help you with your advocacy work.

5.4 Chapter Summary

This chapter discussed the findings from the demographic survey. Most of the participants were female, heterosexual, Caucasian, university educated, employed, and with a household income of $100,000+. It is likely easier to do advocacy work within academia and mental health organizations because there might already be systems in place to do advocacy work, and it might be within the organization's mandate to do advocacy work. It is likely more difficult to do advocacy work in underfunded non-profit organizations due to understaffing and the staff hours required to secure funding. Racialized participants commented on the importance of seeing themselves represented in advocacy communities. Racialized advocates have a better understanding of the unique needs of racialized communities and can be a voice for those communities.

This chapter also discussed the findings from the interviews. Participants got involved in advocacy work through school, work, and volunteering. They were motivated to do advocacy work because of their own lived experience and desire to help others. Their advocacy work focused on education, peer support, increasing collaboration across sectors, and policies. The personal challenges participants experienced while doing advocacy work included vicarious trauma and other negative impacts in their lives. The systemic challenges included government changes and bureaucracy, priorities, and funding. They also highlighted that mental healthcare is biomedical and paternalistic, actions are performative, and mental illness is stigmatized. Funding, community, and personal factors enabled them to do their advocacy work. Advocacy work helped participants find meaning in difficult experiences, a sense of purpose, and other personal rewards. Participants' advocacy work has made impacts through policy change, service creation, organizational change, awareness raising, and helping others. Promising approaches for improving mental healthcare and policy are increasing funding, increasing supports, greater

collaboration in the sector, and including people with lived experience in decision-making. Participants said policies are framed in a biomedical, paternalistic way and there are problems with the way policies are implemented. Participants encourage people who want to do advocacy work to practice self-care, have their voice heard, and build relationships.

CHAPTER 6: DISCUSSION

6.1 Introduction

The first section of this chapter will summarize the major themes identified in the findings and how they relate to Mad Studies. The major themes include the importance of lived experience, epistemic injustice in mental healthcare, tokenism in mental healthcare, challenging the biomedical model, and stigma and the silencing of experience. The second section will outline the findings implications for mental healthcare and policy. Mental healthcare can be improved by co-producing mental healthcare and policy with people with lived experience of mental health challenges. The final section will focus on the findings and implications for future research.

The findings chapter exhibited tensions between participants whose perspectives aligned more closely with dominant mental health narratives and those whose perspectives aligned more closely with Mad Studies. Participants whose views reflected dominant narratives often emphasized stigma, long wait times, and barriers to accessing services as the primary reasons individuals do not seek or receive mental healthcare. In contrast, participants whose views aligned more closely with Mad Studies questioned the assumption that greater access to services is inherently beneficial since they focused on the ways that mental healthcare services can be harmful, coercive, or violent. Mad Studies related critiques are explored in greater depth in this chapter.

6.2 The Importance of Lived Experience

Participants emphasized that lived experience is a powerful motivator and asset in advocacy work. They argued that those with firsthand experience of mental health challenges can better relate to the people they support, understand their needs, and navigate the mental healthcare system. Participants said that people with lived experience can often drive greater

change because their stories are relatable, impactful, and it puts a real face to the issues being addressed. The idea that people with lived experience can be powerful advocates for change aligns with Mad Studies. Mad Studies critically examines the concepts of madness and mental health through the lens of lived experience, social justice, and resistance to psychiatric dominance (Reaume, 2022). The field is rooted in activism that focuses on rights, equity, and justice for people who have been oppressed by psychiatric systems (Menzies et al., 2013). It emphasizes collective advocacy and community-based knowledge (Russo, 2022). It often criticizes clinical models of care and instead promotes peer-led movements, activist scholarship, and grassroots organizing led by psychiatric survivors and mad-identified people (Beresford 2020; Penney, 2022).

In recent years, there has been growing recognition of the critical role that people with lived experience of mental health challenges play in shaping mental healthcare and policy. This marks a shift from viewing service users as passive recipients of care to acknowledging them as experts by experience (Bocking et al., 2019; Roennfeldt & Byrne, 2020). People with lived experience are increasingly seen as contributing to systemic change, influencing policies, guiding mental healthcare reforms, and advocating for rights-based approaches (Sartor, 2023; Sunkel & Sartor, 2022). Their leadership challenges inequalities and pushes for inclusion where no decisions are made without the input of those directly affected (Sartor, 2023).

People with lived experience have knowledge of navigating the mental healthcare system, recovering from mental health challenges, and an understanding of how to improve mental healthcare services. When mental health services are created with the input of people with lived experience, they are more likely to be aligned with the needs of people experiencing mental distress (Hawke et al., 2023). The insights of people with lived experience can offer practical and

cost-effective solutions to problems in the mental healthcare system that mental healthcare professionals might overlook (Schweizer et al., 2018; Sunkel & Sartor, 2022). The expertise of people with lived experience is distinct from academic or clinical knowledge and can play a central role in improving mental health outcomes (Davis et al., 2022; Schweizer et al., 2018). When people with lived experience are involved in delivering mental healthcare services, it can promote human rights and equity, offer hope and connection through shared narratives, challenge biomedical understandings of mental illness, and foster more person-centred approaches to mental healthcare services (Bocking et al., 2019; Marino et al., 2016; Ridley et al., 2017; Schweizer et al., 2018; Sunkel & Sartor, 2022). The inclusion of people with lived experience in the mental healthcare system should be essential because their presence creates positive changes in mental healthcare and policy.

6.2.1 Global Recognition and Support for Lived Experience

There is growing global consensus on the essential role of people with lived experience in transforming the mental healthcare system. Across practice, policy, advocacy, and research, lived experience is increasingly recognized as vital for creating inclusive, equitable, and effective mental healthcare services (Bocking et al., 2019; Montague-Cardoso, 2024; Sartor, 2023; Sunkel & Sartor, 2022). International frameworks and organizations such as the World Health Organization, the United Nations, and the Lancet Commission have encouraged the inclusion of people with lived experience in decisions related to mental healthcare. The World Health Organization's *World Mental Health Report* and the Lancet Commission on *Ending Stigma and Discrimination in Mental Health* emphasize that people with lived experience are essential for change because they have practical insight on how to improve the mental healthcare system (Sartor, 2023). The United Nations' Sustainable Development Goal 3 on health and well-being

calls for inclusive mental health policies shaped by those with lived experience (Montague-Cardoso, 2024). It recognizes their contributions as integral to achieving health equity and reducing stigma (Montague-Cardoso, 2024).

Through their global advocacy efforts, people with lived experience have pushed for mental health to be a bigger priority on national and international agendas (Sunkel & Sartor, 2022). According to the World Health Organization, advocacy by people with lived experience has been instrumental in achieving improvements in mental healthcare legislation, policy, and mental health service delivery (Sunkel & Sartor, 2022). People with lived experience are also able to highlight how social and structural determinants affect mental health (Montague-Cardoso, 2024). This leads to a more holistic understanding of mental health and offers perspectives that can reshape mental healthcare to be more responsive, culturally relevant, and just. Listening to the voices of people with lived experience will allow us to work toward dismantling structural barriers, reducing global disparities in care, and ensuring access to fundamental human rights (Montague-Cardoso, 2024).

6.3 Epistemic Injustice in Mental Healthcare

Epistemic injustice is the devaluation of certain groups' knowledge due to social prejudices, such as those associated with mental illness, race, or gender. (Ridley et al., 2025; Samra, 2025). Epistemic injustice leads to a credibility hierarchy where the voices of mental healthcare professionals are privileged over the voices of people experiencing mental health challenges (Banfield & Palmer, 2025; Samra, 2025). The insights of people with lived experience are often ignored, dismissed, or filtered through a lens of pathology by mental healthcare professionals who have institutional credibility (Banfield & Palmer, 2025; Ridley et

al., 2025). These power dynamics distort collective understandings of mental health by filtering them through narrow and oppressive frameworks (Samra, 2025).

In the interviews, participants highlighted that professional knowledge is often valued more than lived experience which leads to epistemic injustice. They argued that people with lived experience should be viewed as equal partners, but this is not always the case due to the hierarchal nature of psychiatry and academia. Participants believe that epistemic injustice creates challenges for equitable collaboration. Epistemic injustice is a central concern in Mad Studies (White, 2022). It criticizes psychiatry and academia for not valuing the knowledge and experiences of people who struggle with mental health challenges and for creating systems that are hierarchical and oppressive (White, 2022). Mad Studies challenges the authority of mental healthcare professionals and academics who dominate mental health discourse (Eromosele, 2022). Mad Studies advocates for people with lived experience to be viewed as equal partners and legitimate knowledge creators (Eromosele, 2022).

Incorporating the perspectives of people with lived experience of mental health challenges in mental healthcare and policy is a form of epistemic justice. It challenges the norms of whose knowledge is valued and expands the framework of what counts as legitimate understanding in mental healthcare (Ridley et al., 2025; Samra, 2025). Epistemic injustice in mental healthcare is entrenched within a dominant biomedical paradigm that frames distress as individual pathology (Ridley et al., 2025). Lived experience testimony challenges the dominance of biomedical narratives and reveals aspects of mental distress that are overlooked in clinical settings (Ridley et al., 2025). Elevating the voices of people with lived experience in mental healthcare challenges the pathologization and silencing of their voices and creates space for multiple ways of knowing. To meaningfully address epistemic injustice, we need to include

people with lived experience and center their insights in how knowledge is created, shared, and implemented.

6.4 Tokenism in Mental Healthcare

Tokenism is the superficial inclusion of people with lived experience in a way that does not meaningfully redistribute power or value their knowledge (Armstrong & LeFrancois, 2022). Participants expressed concern that even when people with lived experience are included in decision-making, their voices are often ignored, co-opted, or tokenized. They shared that peer support workers are sometimes dismissed or misunderstood in clinical settings, despite being hired specifically for their unique perspective. Inclusion efforts may create the appearance of change without actually shifting power or structure. This leads to tokenism where individuals are used to represent broader groups without meaningful influence. Participants stressed the need for more critical, collective voices and cautioned against assuming one person's experience can represent all people with lived experience.

Mad Studies critiques the tokenistic inclusion of people with lived experience in mental healthcare. Mad scholars argue that tokenistic inclusion often reinforces existing hierarchies rather than dismantling them (Voronka, 2016). The voices of people with lived experience are often co-opted to match the agenda of institutions rather than being highlighted as resistant forms of knowledge (Voronka, 2017). Mad Studies scholars have also spoken out about how peer support roles are medicalized, made less radical, and seen as having less credibility than mental healthcare professionals (Fabris, 2013). Mad Studies emphasizes that diverse and collective mad voices should be used to redistribute power and create structural change (Beresford, 2020).

Harris et al. in their 2023 study found that people with lived experience of mental health challenges who were invited to contribute to continuing professional development initiatives felt

that they were included in performative ways. They were typically involved in a lecture to tell their story and were not involved in planning or delivering education. The storytelling can be empowering, but it reinforces rather than disrupts power imbalances because it fits into the pre-existing curriculum. This can create the illusion of inclusion while maintaining professional dominance and ignoring the voices of people with lived experience. Similar patterns of tokenistic involvement appear in mental healthcare research and policy since people with lived experience are often only included to satisfy representation requirements (Alfia-Burstein et al., 2025).

Meaningful participation of people with lived experience requires power sharing. Inclusion should not rely on the willingness of traditional powerholders to make space for people with lived experience but on creating new spaces that are led by people with lived experience (Banfield & Palmer, 2025). Banfield and Palmer (2025) argue that the metaphor of having a seat at the table is limiting because it implies that people with lived experience should adapt to existing systems. Instead, new tables should be created by people with lived experience to ensure that participation is meaningful instead of performative. The assumption that people with lived experience need to be extensively trained and brought up to speed takes attention away from the need to prepare mental healthcare professionals to learn from people with lived experience (Harris et al., 2023).

In order to overcome tokenism, the engagement of people with lived experience should be relational, reciprocal, and involve power sharing. People with lived experience should be involved early on in decision-making processes (Harris et al., 2023). The voices of all people with lived experience should be valued equally, not just the voices of people who are professionally acceptable because of their education, communication style, and familiarity with clinical language (Harris et al., 2023). Tokenism undermines the legitimacy and impact of

involving people with lived experience in mental healthcare. Engagement of people with lived experience is often framed as inclusive but it frequently reinforces existing hierarchies and devalues lived experience knowledge. Overcoming tokenism requires changing engagement practices so that they are centered on power-sharing, mutual respect, and systemic change.

Collective organizing among people with lived experience, their care givers, and allies plays an important role in overcoming tokenism because it provides a collective voice that includes diverse perspectives. Examples of collective organizing can be found in section 3.5.2. Collective organizing can turn isolated experiences of harm, discrimination, or neglect into shared demands for accountability, better treatment, and protection of rights. Collective organizing can also lead to creating new narratives about mental health, alternative forms of care, changes in policies and institutional practices to ensure that the needs of people experiencing mental distress are met.

6.4.1 Fair Renumeration

Participants argued that people with lived experience should also be paid and included in governance structures. People with lived experience face structural issues like unequal compensation and job insecurity. Mad Studies also critiques the expectation that people with lived experience share their expertise freely while other professionals are compensated (Armstrong & LeFrancois, 2022). These issues are part of a broader neoliberal system that marginalizes mad people through precarious labor conditions (Voronka, 2017).

People with lived experience are frequently expected to participate without pay which reinforces tokenism and inequity (Sartor, 2023). The expectation that people with lived experience should contribute as volunteers rather than paid professionals undermines their status as experts and perpetuates power imbalances (Sartor, 2023). People with lived experience should

receive renumeration for their contributions which signals that their contributions are truly valued (O'Brien & Davenport, 2024; Tizaa et al., 2025). Payments should be equitable and cover hidden costs like internet and health insurance (O'Brien & Davenport, 2024; Tizaa et al., 2025). Lived experience expertise should be recognized, valued, and fairly compensated like any other professional contribution.

International frameworks such as the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Rights of Persons with Disabilities (CRPD) support fair compensation of people with lived experience (Sartor, 2023). ICESCR Article 7 affirms the right to fair wages and equal remuneration for work of equal value (Sartor, 2023). Article 27 of the CRPD explicitly protects the rights of people with psychosocial disabilities to fair and equal employment, including adequate remuneration (Sartor, 2023). These instruments provide a foundation for demanding change in how people with lived experience are compensated for their time and expertise.

People with lived experience who are paid for their contributions report feeling recognized, validated, and hopeful about building careers in mental healthcare (Sartor, 2023). In Sartor (2023) a participant shared that being paid enhanced their self-confidence and affirmed the value of their expertise which opened up new opportunities for meaningful work. In contrast, the absence of pay communicates that lived experience is secondary, emotional, or supplementary rather than legitimate knowledge that deserves respect and investment (Sartor, 2023). Failure to compensate people with lived experience perpetuates tokenism and undermines efforts toward equity, inclusion, and justice in mental healthcare. Upholding the principle of equal pay for equal work is both a human rights obligation and a practical step toward valuing the expertise of people with lived experience.

6.5 Challenging the Biomedical Model

Participants criticized the mental healthcare system as being dominated by a biomedical and paternalistic model. They expressed frustration that advocacy rooted in social justice is often misinterpreted through a narrow medical lens which reduces complex experiences to chemical imbalances. This framing limits meaningful change, stigmatizes individuals, and overemphasizes medication as the primary solution. Policies were seen by participants as too clinical and disconnected from lived experiences which reinforces the idea that people are ill and justifies coercive treatments that strips them of their autonomy.

Mad Studies rejects the dominant biomedical framing of mental health which reduces emotional distress to chemical imbalances or brain diseases (Menzies et al., 2013). Instead, Mad Studies promotes understanding madness and distress within the contexts of social injustice, trauma, poverty, racism, ableism, and colonialism (Eromosele, 2022; Gorman & LeFrancois, 2018; Joseph, 2022). Mad Studies scholars are against involuntary treatment, forced medication, and institutional control (Daley et al., 2019). They argue that psychiatry frames mental distress as individual pathology to justify coercive practices and exercise social control (Daley et al., 2019).

The biomedical model prioritizes diagnosis and symptom management over relational or holistic understandings of mental health which undermines the value of lived experience and personal recovery narratives (Roennfeldt & Byrne, 2020). Ridley (2017) argues that the biomedical focus in mental healthcare is incompatible with prioritizing lived experience. The biomedical model's dominance challenges the integration of lived experience which leads to concerns about the co-option of non-clinical roles and the dilution of their transformative

potential (Roennfeldt & Byrne, 2020; Ridley, 2017). This highlights a need for more holistic approaches in mental healthcare.

6.6 Stigma and the Silencing of Experience

Stigma is defined as a form of severe social disapproval rooted in ignorance and fear (Marino et al., 2016). It is associated with shame, disempowerment, and is often described as a type of social death due to the deep psychological and social pain caused by exclusion and rejection (Marino et al., 2016). Both the experience and fear of stigma are linked to social isolation, avoidance of care, and missed life opportunities (Marino et al., 2016). Its pervasive effects span all aspects of life for those with mental illness and may be more disabling than the illness itself (Bocking et al., 2019). Mental illness-related stigma is present among mental healthcare professionals which acts as a barrier to recovery and treatment access (Arblaster et al., 2023). Factors contributing to stigma in clinical environments include negative attitudes, lack of knowledge, therapeutic pessimism, and unsupportive workplace cultures (Arblaster et al., 2023).

Participants described how mental illness stigma creates significant personal and professional risks for people in advocacy roles. They feared being perceived as incompetent, weak, or emotionally unstable, which could impact their employment and relationships. Advocating publicly meant facing increased vulnerability and judgment. Participants highlighted that society often holds harmful assumptions that mental health challenges result from poor choices, are not normal human experiences, or that people must be in crisis to be taken seriously. Participants emphasized the need to reduce stigma and challenge dangerous stereotypes since people experiencing mental illness are often feared unnecessarily. They called for greater public education and understanding so that people feel safe to seek help and are treated with dignity.

Mad Studies critiques how psychiatric labels are used to discredit, control, and silence people (Pilling, 2022). Mad Studies rejects simplistic, medicalized, and moralistic narratives about madness such as madness being caused by poor choices or individual pathology (Burstow et al., 2014). Mad Studies advocates to normalize and humanize diverse experiences of mental distress and to understand them as a result of the social, economic, and environmental contexts of people's lives (Redikopp, 2021).

Research supports that contact with individuals with lived experience is among the most effective ways to reduce stigma (Wainwright et al., 2025). Lived experience is increasingly recognized as an essential asset in shaping mental health education because it exposes students to real-world lived experiences of recovery to challenge stigmatizing beliefs (Arblaster et al., 2023; Wainwright et al., 2025). Biomedical models of mental illness might reinforce stigma by implying that people with mental illness are fundamentally different (Bocking et al., 2019). However, direct and personal engagement with people labeled with mental illness is shown to effectively challenge and reduce stigma (Bocking et al., 2019).

6.7 Implications for Practice: Advancing Co-Production

Participants emphasized the importance of including people with lived experience in decision-making processes. They advocated for creating systems that genuinely make space for lived experience, rather than expecting individuals to conform to existing psychiatric or academic norms. Suggestions included co-producing knowledge and services, involving lived experience researchers in research teams, and giving mental health service users more say in their own treatment. The goal is meaningful collaboration between those with lived and professional expertise to improve mental healthcare and policy. Mad Studies is also in favour of co-production practices that involve sharing power, control, resources, and risks (Carr, 2022).

Transformative co-production requires equally valuing the knowledge of people with lived experience, dismantling hierarchies, and recognizing oppressive psychiatric practices (Carr, 2022).

Co-production is a form of participatory engagement where people with lived experience work as equal partners from the very beginning of a project (Arblaster et al., 2023). Co-production is about power sharing in decision-making to move beyond tokenistic consultation to genuinely valuing lived experience as a form of expertise (Harris et al., 2023). People with lived experience should be involved in shaping research questions, designing methodologies, and making budgeting decisions rather than being brought in after the key decisions have been made (Harris et al., 2023; O'Brien & Davenport, 2024; Tizaa et al., 2025). This improves recruitment, methodology, and dissemination (Davis et al., 2022; Sheikhan et al., 2025). It also demonstrates that people with lived experience are fully involved in knowledge creation and addresses historical exclusion practices (Hawke et al., 2023; Sheikhan et al., 2025). The process should also be mutually beneficial, help build relationships, and validate the strengths of all involved (Arblaster et al., 2023).

People with lived experience should be offered flexible work schedules, longer timelines, and reasonable accommodations to ensure they can contribute fully without negative impacts to their wellbeing (Tizaa et al., 2025). People with lived experience should be provided with training to ensure they have the skills to participate equally (Tizaa et al., 2025). The people they work with should also be provided with training to ensure they are able to share power and work respectfully with people with lived experience (Tizaa et al., 2025).

Inclusive methodologies could be used such as arts-based and creative methods because they facilitate communication, build safe spaces, and allow different forms of knowledge to be

heard and valued (Tizaa et al., 2025; Veldmeijer et al., 2023). Co-designed resources and interventions are better tailored to community needs which leads to higher quality and more sustainable outcomes (Arblaster et al., 2023; Veldmeijer et al., 2023). Co-production ensures studies and interventions are aligned with community priorities which enhances their relevance, feasibility, and implementation (Hawke et al., 2023; Sheikhan et al., 2025). People with lived experience from diverse socioeconomic backgrounds should be recruited to ensure that different perspectives are represented (Hawke et al., 2022; Tizaa et al., 2025).

The process of co-production can be empowering for people with lived experience because it offers personal benefits, a sense of pride, and positive impacts to their mental health (Arblaster et al., 2023; Veldmeijer et al., 2023). It can also build skills, confidence, and career pathways for them (Tizaa et al., 2025). Co-production reduces stigma, builds respect, and bridges the gap between academic theory, clinical practice, and community reality (Arblaster et al., 2023; Harris et al., 2023). Meaningful inclusion can also reduce stigma and social distance (Harris et al., 2023).

6.8 Implications for Policy: Embedding Lived Experience in Decision-Making

Participants emphasized the importance of including lived experience perspectives in policy making to ensure that decisions reflect the needs of service users. They mentioned that there are some policies and structures like advisory boards and stakeholder consultations to promote inclusion in Ontario. However, access to these opportunities are limited and often rely on informal networks or self-initiative which can result in the same people being repeatedly consulted. There are also significant challenges with policy implementation. These include inconsistent interpretations, lack of monitoring and evaluation, and unclear guidance on applying international frameworks such as the United Nations Convention on the Rights of Persons with

Disabilities within Canadian law. These issues raise concerns about how effectively policies protect and support service users in practice.

Mad Studies insists that mad, psychiatric survivor, and service user voices be incorporated into the design of services and policies (Carr, 2022). Mad Studies warns that consultation without redistribution of power reinforces existing hierarchies (Carr, 2022). Mad Studies is also critical of policy frameworks that claim to protect rights but fail in practice (Beaupert & Brosnan, 2022). Mad Studies often engages critically with disability rights law and highlights how human rights are often poorly integrated or inadequately enforced in national legal systems (Beaupert & Brosnan, 2022).

6.8.2 "Nothing About Us Without Us": A Principle for Inclusive Policies

The contemporary movement for the inclusion of people with lived experience in mental healthcare and policy is rooted in the long-standing activist ethos of "nothing about us without us" (Speyer et al., 2025). This principle emerged in the 1960s from the disability rights movement to asset that exclusion is a form of oppression, lived experience is a legitimate source of expertise, and disabled people must lead decisions about disability policy, services, and research (Charlton, 1998). It was also adopted by the psychiatric survivor and consumer movements to resist the marginalization and criminalisation of people labeled as mentally ill (Speyer et al., 2025). These grassroots movements challenged traditional power dynamics in mental healthcare and demanded that people with lived experience have agency in decisions affecting their lives (Speyer et al., 2025). The slogan "nothing about us without us" advocates for co-production and leadership by those with lived experience in all areas of mental healthcare, policy, and research (Tizaa et al., 2025). Co-production of policies would involve including people with lived experience throughout the policy process rather than just having them consult

at certain stages of the policy process. The principle has been operationalised through the inclusion of lived experience researchers who bring direct knowledge of mental illness to their roles (Tizaa et al., 2025). These researchers are increasingly recognised as experts by experience and are valued for their unique insights into mental health research (Tizaa et al., 2025). Embedding “nothing about us without us” into mental healthcare and policy affirms the right of people with lived experience to shape the systems that affect them.

6.9 Directions for Future Research

The findings from this study highlight several important areas for future research. Given that the majority of participants were female, heterosexual, Caucasian, university educated, employed, and had household incomes of $100,000 or higher, future studies should include more diverse participant samples. This would allow for a more comprehensive understanding of advocacy experiences across intersecting identities such as race, socioeconomic status, gender identity, and education level. Racialized participants emphasized the importance of seeing themselves reflected in advocacy spaces. Future research should explore the experiences of racialized advocates in greater depth to identify ways to better support them in their advocacy efforts and improve outcomes for their communities. Future research could also explore the personal and psychological dimensions of advocacy work. The current findings reveal that advocacy work entails both emotional challenges, like vicarious trauma, and personal rewards, such as finding meaning and purpose. Research that explores the role of faith and spirituality in advocacy could be conducted as well. Investigating strategies that promote advocate well-being including self-care practices, peer support, and community connection could provide valuable insight into how to support and retain advocates in mental healthcare and policy.

Given that there were tensions between mad perspectives and other advocacy perspectives, this could be another area of research to explore. Different advocacy models could be described and evaluated to determine their ability to create change that meets the needs of people experiencing mental distress. There should also be more research about the systemic barriers that shape advocacy work in mental healthcare and policy. Future studies could focus on how biomedical and paternalistic approaches within mental healthcare and policy constrain advocacy efforts and how more collaborative, holistic, and trauma-informed frameworks might be implemented. This could involve researching different approaches to co-production and exploring the advocacy experiences of people who are involved in co-production projects.

Overall, future research should continue to examine advocacy from a systems perspective by integrating the voices of those with lived experience and focusing on structural, organizational, and individual factors that enable sustainable, equitable, and effective advocacy in mental healthcare and policy.

6.10 Chapter Summary

The major themes highlighted in this chapter are the importance of lived experience, epistemic injustice in mental healthcare, tokenism in mental healthcare, challenging the biomedical model, and stigma and the silencing of experience. Participants highlighted the important role that people with lived experience play in advocating for improvements to mental healthcare and policy. They have encountered epistemic injustice when doing advocacy work because the knowledge of mental healthcare professionals was valued over their lived experience knowledge. They also encountered tokenism where they were included in initiatives in ways that felt performative and that did not give them enough power to make meaningful changes. Participants commented that mental healthcare and policy are dominated by the biomedical

model of mental illness which is disconnected from the experiences of people with mental distress and does not provide them with the support they need. They also highlighted how stigma makes people hesitant to take on advocacy roles and seek help when they are struggling with mental health challenges.

One strategy for improving mental healthcare is to co-produce mental healthcare and policy with people with lived experience of mental health challenges. This ensures that they are involved in projects in significant ways that lead to positive outcomes and centers the voices of people with lived experience. Policies should be guided by the principle of nothing about us without us to ensure that people with lived experience are involved in decisions that affect their lives. Future research should include people with lived experience of mental health challenges from diverse socio-economic backgrounds. The personal and psychological dimensions of advocacy work could be further explored as well. Future studies can also investigate how the biomedical model of mental illness negatively effects the advocacy efforts of people with lived experience and how co-production can be used to improve the outcomes of people experiencing mental distress.

CHAPTER 7: CONCLUSION

This dissertation has contributed to the literature by specifically focusing on the advocacy experiences of mental health service users who tried to improve mental healthcare and policy in Ontario. In alignment with Mad Studies, this research study has created knowledge that privileges the experiences and wisdom of people who have used mental health services and challenged biomedical narratives that dominate mental healthcare and policy. The research study has highlighted mental health service user motivations, rewards, work, impact, facilitators, and barriers of their advocacy efforts as well as recommendations for improvement to mental healthcare and policy. Co-production was highlighted as a way to improve mental healthcare services so that they are better able to meet the needs of mental health service users. Overall, this research study has outlined promising approaches for improving mental healthcare and policy in Ontario.

This research study also expands on the importance of lived experience by highlighting the types of lived experience that need to be included in decisions affecting mental healthcare and policy. Incorporating lived experience expertise into mental healthcare and policy is imperative because it offers an in depth understanding of navigating mental health challenges and the mental healthcare system. People with lived experience should be involved in every stage including design, implementation, and evaluation rather than consultation or tokenistic roles to ensure that they have real influence on mental healthcare and policy. Equally important is protecting lived experience contributions from being diluted or co-opted to fit institutional agendas. People with lived experience from diverse socio-economic backgrounds and perspectives should be included in decision-making processes to challenge dominant narratives. When lived experience is recognized as a valid source of knowledge it can strengthen mental

healthcare and lead to policies that genuinely meet the needs of people experiencing mental distress.

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APPENDICES

Appendix A: Recruitment

Websites

Kijiji www.kijiji.ca/

Craigslist https://toronto.craigslist.org/

Madness Canada https://madnesscanada.com/

Mad Studies Hub at York University https://www.yorku.ca/research/madstudieshub/

Mental Health Organizations

Canadian Mental Health Association, TAIBU Community Health Centre, Alternatives, Talking About Mental Illness Coalition, Eviance Disability, Centre for Addiction and Mental Health, Gerstein Crisis Centre, The Canadian Alliance on Mental Illness and Mental Health, Sound Times, Working for Change, Parkdale Activity Recreation Center, Northern Initiative for Social Action, Ontario Psychiatric Patient Advocate Office, Krasman Centre, Mental Health and Addictions Centre of Excellence, AccessMHA, Can-Voice, Ontario Psychological Association, Ontario Association of Mental Health Professionals, ConnexOntario, Across Boundaries, Distress Centres of Greater Toronto, Hong Fook, Wanasah, Project LETS, Collective Justice, Healthful Chat, Abolition and Disability Justice, Suicide Crisis Hotline, National Initiative on Eating Disorders, Institute for Advancements in Mental Health, Ontario Shores, WayPoint, Emotions Anonymous, JACS Toronto, Hope and Me, The Jean Tweed Center, Parents for Children's Mental Health, Royal Ottawa Mental Health Center, Friendship Bench, Mental Illness Caregivers Association of Canada, Peer Support Canada, Peer Works, Mental Health Commission of Canada, Support House, The Ontario Caregiver Organization, Bounce Back,

Distress and Crisis Ontario, Children's Mental Health Ontario Centres, and Mental Wellness Peer to Peer Support Groups.

Hospitals

University Health Network, SickKids Hospital, Mount Sinai Hospital, Unity Health, Sunnybrook Health Sciences Centre, Scarborough Health Network, Trillium Health Partners, Women's College Hospital, Michael Garron Hospital, Humber River Health, North York General Hospital, Stevenson Memorial Hospital, Royal Victoria Regional Health Centre, William Osler Health System, Collingwood General and Marine Hospital, Muskoka Algonquin Healthcare, Oak Valley Health, Southlake Regional Health Centre, Halton Healthcare, Headwaters Health Care Centre, Orillia Soldiers' Memorial Hospital, Waypoint Centre for Mental Health, Mackenzie Health, Almonte General Hospital, Quinte Health, Campbellford Memorial Hospital, Northumberland Hills Hospital, Cornwall Community Hospital, Deep River and District Health, Hawkesbury and District General Hospital, Kemptville District Hospital, Kingston Health Sciences Centre, Ross Memorial Hospital, Lakeridge Health, Children's Hospital of Eastern Ontario-Ottawa Children's Treatment Centre, Queensway-Carleton Hospital, Bruyere Continuing Care Inc., Hôpital Montfort, Royal Ottawa Health Care Group, Pembroke Regional Hospital Inc., Peterborough Regional Health Centre, Renfrew Victoria Hospital, Perth and Smiths Falls District Hospital, Winchester District Memorial Hospital, Services De Sante De Chapleau Health Services, Espanola General Hospital, Hornepayne Community Hospital, Blanche River Health, Santé Manitouwadge Health, Temiskaming Hospital, Mattawa Hospital, North Bay Regional Health Centre, West Parry Sound Health Centre, Smooth Rock Falls Hospital, West Nipissing General Hospital, Timmins and District General Hospital, Health Sciences North, and Lady Dunn Health Centre.

University Departments

York University (Anthropology, Equity Studies, Humanities, Philosophy, Liberal Arts and Professional Studies, Social Science, Psychology, Social Work, Sociology, and Student Wellness), University of Toronto (The Buddhism, Psychology and Mental Health Program Critical Studies in Equity and Solidarity, Health Studies, Psychology, Sociology, and Women and Gender Studies), Toronto Metropolitan University (School of Disability Studies, Psychology, and Social Work), Trent University (Gender and Social Justice, Health and Behaviour, Psychology, Social Work, and Sociology), University of Windsor (Psychology, Social Work, Interdisciplinary and Critical Studies, and Sociology), Ontario Tech University (Social Science and Humanities), Algoma University (Cross Cultural Studies, Community Economic and Social Development, Psychology, Social Work, and Sociology), Brock University (Psychology, Sociology, and Women and Gender Studies), Carleton University (Sociology, Feminist Institute of Social Transformation, Institute of Disciplinary Studies, Psychology, and Social Work), Lakehead (Psychology, Gender and Womens Studies, Social Work, and Sociology), Laurentian (Equity, Diversity, and Human Rights, Psychology, Sociology, and Social Work), McMaster University (Psychology, Social Work, and Sociology), Nipissing University (Gender Equality and Social Justice, Psychology, Social Welfare and Social Development, and Social Work), Queens University (Gender Studies, Psychology, and Sociology), University of Guelph (Psychology and Sociology), University of Ottawa (Faculty of Social Sciences), University of Waterloo (Gender and Social Justice, Psychology, Peace and Conflict, Social Work, and Sociology), Western University (Gender, Sexuality, and Women Studies, Sociology, and Psychology), and Wilfred Laurier University (Psychology, Social Work, Sociology, and Women and Gender Studies).

Appendix B: Demographic Survey

Thank you for participating in the research study titled Exploring the Experiences of Mental Health Service Users Advocating for Changes in Mental Healthcare and Policy in Ontario. As part of this study, you are being asked to complete the following demographic survey. You can skip any question if you do not wish to answer it.

1. What is your name? Open ended answer.
2. What is your age? Open-ended answer.
3. What city do you live in? Open ended answer.
4. What is your sex? Options male or female.
5. What is your gender identity? Open-ended answer.
6. What is your sexual orientation? Open-ended answer.
7. How would you describe your race/ethnicity? Open-ended answer.
8. What is the highest level of education you have completed? Options less than high school, high school or equivalent, vocational training, college diploma, Bachelor's degree, Master's degree, Doctorate.
9. What is your employment status? Options employed full-time, employed part-time, unemployed, student, on leave, self-employed.
10. What is your household income? Options $0k to $30k, $30k to $70k, $70k to $100k, over $100k.

Appendix C: Interview Guide

Background:

1. Can you tell me about the advocacy work you have done to improve mental healthcare and policy in Ontario? (Prompt: How long have you been doing advocacy work?)
2. How have your own experiences/social positioning influenced your decision to engage in advocacy? (Prompt: Did your own experiences with mental healthcare influence your decision to engage in advocacy work? Do you think your (insert social position) has influenced your decision to do advocacy work?)
3. How were you empowered to do advocacy work to improve mental healthcare and policy in Ontario? (Prompts: How did you get involved in doing advocacy work? Who or what inspired you to do advocacy work? What were/are you hoping to achieve?)

Challenges and Strengths:

1. What were the challenges associated with doing advocacy work? (Prompts: What were the personal challenges? What were the systemic challenges? What challenges does the current system create?)
2. What are the rewards of doing advocacy work? (Prompt: What did you personally gain from doing advocacy work? Is it easy to do advocacy work within the current system?)

Impact:

1. What impact has your advocacy work made on mental healthcare and policy? (Prompt: Can you give some concrete examples of changes that have resulted from your advocacy?)

Promising Approaches Mental Healthcare:

1. What are promising approaches for improving mental healthcare? (Prompts: What are promising approaches for improving access to mental healthcare? What are promising approaches for improving the mental health service user experience?)
2. How can mental health service user experience be used to improve mental healthcare?
3. What advice would you give to other individuals who want to do advocacy work to improve mental healthcare in Ontario?

Promising Approaches Policy:

1. Are you aware of any policy mechanisms that can be used to include the voices of people with lived experience? (Prompts: How did you find policy problems were framed? Did you think such framing limited the policy process?)
2. What are promising approaches for improving mental healthcare policy?
3. What advice would you give to other individuals who want to do advocacy work to improve mental healthcare policy in Ontario?