# TROUBLING PEER SUPPORT INSTITUTIONALIZATION:

## A MAD INSTITUTIONAL ETHNOGRAPHY;

Or,

# EVERYDAY DOCUMENTATION, DE/VALUING, & VALUES WORK IN

## INSTITUTIONALIZED PEER SUPPORT

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## ABSTRACT<sup>1</sup>

This study explores how the everyday work of peer supporters working within institutionalized settings are shaped by institutional forces ("ruling relations"), through a series of four (peer support) focus groups and interviews with five peer support workers in Ontario.

In Chapter 1, I discuss my own experiences as a peer support worker and my motivation for exploring the institutionalization of peer support through this research. I was drawn to explore this topic because of my own experiences of feeling troubled by documentation requirements when providing peer support within a formal healthcare setting. In <u>Chapter 2</u>, I provide a brief history of the emergence of peer support within the psychiatric consumer/survivor movement. In <u>Chapter 3</u>, I explore key turning points through which peer support has started to be seen as a profession ("professionalization") and become embedded within the healthcare system ("institutionalization") in Ontario and Canada more broadly.

In <u>Chapter 4</u>, I describe the theoretical orientation of Institutional Ethnography which grounds this research, through a focus on how everyday work is shaped by various pieces of text (e.g., policies, legislation, and discourse). In <u>Chapter 5</u>, I discuss how I have aimed to bring a "Mad Turn" (Phil Smith, 2017, n.p.) to Institutional Ethnography through an attention to the elements of care, knowledge, and change within peer support, as well as adopting peer support groups as a research method/ology. In <u>Chapter 6</u>, I discuss how I approached the work of preparation and participant recruitment, data

<sup>&</sup>lt;sup>1</sup> Instead of providing both an "abstract" (for academic readers) and "lay abstract" (for general audiences), I have chosen to write a single abstract which I have tried to make accessible to a wide range of readers. To do so, I use plain language whenever possible; when key terms are necessary, I provide a brief definition of terms as they arise.

collection and analysis, and Institutional Ethnography's goal of creating change. Here, I also introduce the peer support workers who participated in the study.

In <u>Chapter 7</u>, I explore peer supporters' approaches to writing, reading, and verbally sharing information about their peers ("documentation work"). In doing so, I reveal how their experiences and "felt troubles" relating to documentation are shaped by ideas of (clinical) confidentiality constructed in the *Personal Health Information Protection Act* (PHIPA; 2004, c.3, Sched. A.). In <u>Chapter 8</u>, I explore how both lived experience and peer support are devalued through the ways organizations and clinicians determine and describe the value of healthcare roles ("de/valuing work"). In doing so, I reveal how peer supporters' experiences of being (de)valued are shaped by discourses of "professional/ism" which equate being a professional to having a post-secondary education and working through clinical frameworks.

In <u>Chapter 9</u>, I describe the work that peer supporters, clinicians, and organizations (can) engage in to ground peer support workers within peer values and approaches ("values work"). This chapter is structured around one participant's suggestion that peer drift can be minimized through peer community and peer culture. In <u>Chapter 10</u>, I draw on these suggestions and the findings of the study to provide recommendations for peer support workers, organizations and clinical workers, the peer support sector as a whole, and research/ers.

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# TABLE OF CONTENTS

ABSTRACT	II
ACKNOWLEDGEMENTS	IV
TABLE OF CONTENTS	VII
FIGURES & TABLES	XI
PREFACE: A NOTE ON LANGUAGE & STYLE	XII
MANUSCRIPT STYLE KEY DEFINITIONS Definitions Related to Institutional Ethnography Definitions Related to Peer Support Institutionalization	XIV <i>xv</i>
CHAPTER 1: BACKGROUND	1
THE HAMILTON MAD STUDENTS' COLLECTIVE: ENTERING THE WORLD OF PEER SUPPORT UNCOVERING A TRIANGLE MODEL OF PEER WORK	4
PEER SUPPORT TRAINING: AN ENTRY POINT TO PEER SUPPORT AS A "PROFESSION" AN ENTRY POINT TO INSTITUTIONALIZED PEER SUPPORT	
CHAPTER 2: PEER SUPPORT HISTORY & SOCIAL MOVEMENT ORIGIN	IS 13
Consumer/Survivor Movement Origins Early Mental Patient Organizing Deinstitutionalization Discourses of Care, Knowledge, and Empowerment in Consumer/Survivor Movement Inconsumer & Sure Hard Automatica	13 14
MOVEMENT HISTORIES & SELF-HELP ALTERNATIVES Part 1 – Critiquing (& Redefining) "Care" Part 2 – Consciousness-Raising & Experiential Knowledge Part 3 – Empowerment & Emancipation	18 20
CHAPTER 3: PROFESSIONALIZATION & INSTITUTIONALIZATION	25
PEER PROFESSIONALIZATION AND INSTITUTIONALIZATION IN ONTARIO, CANADA Defining Professionalization and Institutionalization The Consumer/Survivor Development Initiative (CSDI) The Mental Health Commission of Canada & Peer Support Canada LOOKING FOR TROUBLE: CONCERNS & IMPACTS OF PEER PROFESSIONALIZATION AN	25 27 28
INSTITUTIONALIZATION Part 1: Mutuality?: Recreating Power Imbalances Part 2: "In" But Not "Of" The System: De-emphasizing Experiential Knowledge Part 3: "Agents of Change"?: Individualized Empowerment	31 <i>33</i> e34
CHAPTER 4: EXPLORING INSTITUTIONAL ETHNOGRAPHY	37
INTRODUCING INSTITUTIONAL ETHNOGRAPHY	37

Getting Lost in Institutional Ethnography: Confusion & Finding a Paradigm Shift	t. <i>39</i>
A HISTORICAL EXPLORATION OF INSTITUTIONAL ETHNOGRAPHY	40
Marxist Historical Materialism: Outlining a Social Ontology	41
Feminist Consciousness-Raising: Embracing a Social Epistemology	
RELEVANCE TO RESEARCH TOPIC	44
CHAPTER 5: UNCOVERING A MAD INSTITUTIONAL ETHNOGRAPHY	46
Alignment With Psychiatric Critique	46
ALIGNMENT WITH PEER WORK	47
BRINGING A "MAD TURN" TO INSTITUTIONAL ETHNOGRAPHY	48
Triangular(izing) Epistemology	49
Peer Support as Method/ology	51
CHAPTER 6: DESCRIBING THE EVERYDAY WORK OF RESEARCH	53
PREPARATION	53
Uncovering a Problematic	
Recruitment	
Creating a Peer Support (Group) Environment	
DATA COLLECTION & ANALYSIS	
Facilitating Discussion	
Interrogating Text and Discourse	
Analytical Tools	
Reflection & Review	
NEXT STEPS: WORKING TOWARD CHANGE.	
INTRODUCING THE PEER SUPPORT WORKERS	
CHAPTER 7: TROUBLING DOCUMENTATION WORK	71
"I DON'T READ MY PEERS' CHARTS": REFUSING INSTITUTIONAL ACCOUNTS	
"I JUST WRITE THINGS AS REMINDERS": APPROACHES TO WRITING DOCUMENTATION	
"IT'S UP TO [THE PEER]": CONSENT AND SHARING INFORMATION WITH COLLEAGUES	
"WE'RE NOT THERE TO RAT SOMEONE OUT": OUTLINING PEER CONFIDENTIALITY	75
"ENTITLED TO ASSUME [] IMPLIED CONSENT": CONSTRUCTING CLINICAL	
CONFIDENTIALITY	
DISCUSSION	
OPPORTUNITIES FOR CHANGE	82
CHAPTER 8: DE/VALUING WORK	85
"IT DOESN'T REFLECT THE VALUE OF OUR LIVED EXPERIENCE": DETERMINING	
SALARIES	
"So Is Cleaning Staff": Reinforcing Organizational Hierarchies	87
"MAYBE I'M SUPPOSED TO GET MY SSW NOW": PRESSURES TOWARD FORMAL	0.0
EDUCATION	
"[SHARING] FROM THE INSIDE": LIVED EXPERIENCE AND/AS EDUCATION	90

"Other People's Expertise Don't Compare": Discourses & Disjunctures	OF
PROFESSIONAL/ISM	
DISCUSSION	
OPPORTUNITIES FOR CHANGE	95
CHAPTER 9: VALUES WORK	97
"IT'S HARD BEING A LONE WOLF": EMBRACING PEER COMMUNITY	
"THE SYSTEM TRIES TO GRIND YOU DOWN": FOSTERING PEER CULTURE DISCUSSION	
CHAPTER 10: STITCHING THREADS TOGETHER	105
Reflections	
The Ruling Relations of Confidentiality & Health Privacy Legislation	
Re-Thinking "Professionalism": Peer Support as an "Un/Profession"?	
The Risks of (Re)Presenting Everyday Work as "Best Practices"	
LIMITATIONS	113
From Professionalization to Institutionalization	113
Institutional Ethnography Across Settings	113
Demographic Limitations	115
Geographical Limitations	116
IMPLICATIONS	117
Recommendations from Study Participants	
Recommendations for Peer Support Workers	
Recommendations for Organizations & Clinical Workers	
Recommendations for the Peer Support Sector	
Recommendations for Research/ers	122
CONCLUSION	123
REFERENCES	125
APPENDIX A: MAPS OF DOCUMENTATION, DE/VALUING, AND VAL	UES
WORK	133
APPENDIX B: SUMMARY FOR THE PEER SUPPORT SECTOR	136
DOCUMENTATION WORK	136
Confidentiality	
DEVALUING WORK	
Education & Professionalism	138
VALUES WORK	139
Peer Community	139
Peer Culture	140
MAP OF DOCUMENTATION WORK	141
MAP OF DEVALUING WORK	142
MAP OF VALUES WORK	143

RECOMMENDATIONS FROM STUDY PARTICIPANTS: SUPPORTING PEER SUPPORT WC	ORK
	144
RECOMMENDATIONS FOR PEER SUPPORT WORKERS: PREVENTING PEER DRIFT	144
RECOMMENDATIONS FOR ORGANIZATIONS: FACILITATING PEER COMMUNITY	145
RECOMMENDATIONS FOR ORGANIZATIONS: FOSTERING PEER CULTURE	145
RECOMMENDATIONS FOR THE PEER SUPPORT SECTOR: PREVENTING PEER DRIFT	146
RECOMMENDATIONS FOR RESEARCH: EXPLORE PROFESSIONALIZATION &	
INSTITUTIONALIZATION	146

# FIGURES & TABLES

FIGURE 1: A TRIANGLE MODEL OF PEER WORK	6
FIGURE 2: TRIANGULAR(IZING) EPISTEMOLOGY	50
<b>TABLE 1:</b> RECOMMENDATIONS FROM STUDY PARTICIPANTS	118
<b>TABLE 2:</b> RECOMMENDATIONS FOR PEER SUPPORT WORKERS	118
TABLE 3: RECOMMENDATIONS FOR ORGANIZATIONS – ENABLING PEER COMMUNITY.	119
<b>TABLE 4:</b> RECOMMENDATIONS FOR ORGANIZATIONS – FOSTERING PEER CULTURE	120
<b>TABLE 5:</b> RECOMMENDATIONS FOR THE PEER SUPPORT SECTOR	121
<b>TABLE 6</b> : RECOMMENDATIONS FOR RESEARCH/ERS	122
FIGURE 3: MAP OF DOCUMENTATION WORK	133
FIGURE 4: MAP OF DE/VALUING WORK	134
FIGURE 5: MAP OF VALUES WORK	135

## PREFACE: A NOTE ON LANGUAGE & STYLE

#### MANUSCRIPT STYLE

Drawing on the theorical underpinnings of Instituional Ethnography and Mad Studies, I have made a variety of choices on how this manuscript is written, which I briefly describe below.

I have chosen to follow the feminist practice of identifying authors with their full names in this manuscript, as outlined by Marjorie Devault (1996), to allow authors and their contributions to remain "visible to the reader." For literature with three or more authors, I list all of the authors' names the first time the literature is referenced; for the sake of brevity, further references list only the first author's name (e.g., Shery Mead et al., 2001).

Although I use the language of Mad(ness), I acknowledge that this is not a universal language choice. I use the language of Madness when referencing Mad Studies literature and referring to my own experiences as a Mad person. However, when discussing the experiences and contributions of my participants, I mirror the language that they use, as to not place my own meaning on their experiences.

As a peer support worker myself, I use collective first-person pronouns ("we", "our", "us") to demonstrate my adoption of the standpoint of my study participants (peer support workers). I do this to demonstrate how, as a peer support worker, I am also "hooked into" (Janet Rankin, 2017b, p. 2) a common set of social relations with my study participants. At the same time, I recognize that our experiences are not universal. I do not use this language when referring to experiences which are unique to one or more peer supporters, or when describing things I have not personally experienced.

xii

I use the language of "peer" purposefully, to refer to "an equal, or 'someone like me [(or you)],' with shared social or demographic identity and lived experience" (Shinjini Bakshi, 2021, p. 24) – in this case, a shared lived experience of mental health and/or substance use concerns. In doing so, I use the language of "peer" to refer to both peer support workers, and the peers (service users) they support. I do this to demonstrate how peer supporters adopt the standpoint of their peers in their work, by drawing on their own lived experience – not (only) as a professional, but as a peer. Likewise, I do this to demonstrate how both peer support workers and peers (service users) share similar lived experiences, and are hooked into common sets of social relations – as people accessing services, navigating mental health/substance use, etc. I recognize that at times, this may be confusing. When necessary, I will differentiate by referring to "peers accessing support" or similar language.

At times, I will use more clinical language (such as "patient," "client," or "service user") instead of "peer." I do this when referring to (clinical) texts, in order to preserve (and exemplify) the intended meaning of the text, and in recognition that clinical language is not always directly interchangeable with the language of "peer."<sup>2</sup> Likewise, when referencing clinical relationships, I revert to clinical language, as clinical staff are not (necessarily) "peers" of their clients. The language of "peer" is relational; I use the language of "peer" only in reference to a shared lived experience, including that found within the peer (support) relationship.

<sup>&</sup>lt;sup>2</sup> For example, the *Personal Health Information Protection Act* (PHIPA; 2004, c. 3, Sched. A) is intended to protect the personal health information of "patients." However, not all patients are "peers" (as defined in this manuscript).

I include direct quotes of participants when possible, in order to allow them to describe their experiences in their own words. When participants have not consented to direct quotes being used, I paraphrase their comments. While writing quotes, I use square brackets [like this] to add additional context or clarification when necessary, or to replace words or phrases (for example, replacing identifying information with a generic descriptor). Likewise, I use ellipses within square brackets (e.g. [...]) to indicate that words or phrases have been ommitted in order to improve clarity.

I use capitalization and punctuation to reflect the natural speaking rhythm of participants, with two exceptions. When quotes (or sections of quotes) begin midsentence, I capitalize the first letter of the first word to increase readability. Likewise, when sections have been removed, periods have been added to indicate a new thought or sentence. Other small changes have been made to improve readability and clarity, such as removing repeated words or series of words, unless doing so would impact the meaning of the sentence. When participants reference themselves or another person speaking to someone else (or themselves, as internal monologue), these sections have been italicized and placed within quotation marks, to differentiate between what participants are saying to the group and what conversations they are re-telling.

#### **KEY DEFINITIONS**

Institutional Ethnography uses a variety of "technical term[s]" (Marie Campbell & Frances Gregor, 2002, p. 31), the meanings of which may not be immediately apparent to all readers. In the interest of ensuring this research is accessible to a wide range of readers, and particularly those implicated in the research itself (e.g., peer support workers and organizations), I have included a brief description of some of these key terms below.

xiv

#### Definitions Related to Institutional Ethnography

The term "local" refers to the everyday world of participants, and the setting(s) in which their work takes place. In this study, it refers to the places that peer supporters work. On the other hand, "extra-local" refers to settings that are external to where the work of participants take place. Extra-local settings may be within the same organization (e.g., HR departments) or outside of it (e.g., government). Extra-local work shapes and coordinates what happens in local settings; for example, when the government creates healthcare legislation, this impacts healthcare practices on a local level.

As described by Yang Yann Foo, Kevin Tan, Xiaohui Xin, Wee Shiong Lim, Qianhui Cheng, Jai Rao, and Nigel Tan (2021), a "**standpoint** is a social position of a particular group of people" (p. 508). The work, tensions, experiences, and knowledges of peer support workers in a local setting inevitably differs from those in an extra-local setting (e.g., a hospital's board of directors) – they see and understand work differently from one another.

**Disjuncture** refers to a disconnect between how something is known from an experiential (local) standpoint and from a ruling (extra-local) standpoint. As Marie Campbell and Frances Gregor (2002) note, "the issue of disjuncture is between different versions of reality" (p. 48). Disjunctures commonly create tensions or "troubles" for people in local settings, as ruling and experiential knowledge come into conflict with one another.

A **problematic** "points to problems, tensions, and contradictions that arise in the relations between people and how society is organized" (Yang Yann Foo et al., 2021, p. 508) as a result of disjunctures of knowing. Problematics are grounded in the troubles faced by standpoint participants and used to direct the process of inquiry, in order to discover how their work is organized to produce the tensions that is does.

**Texts** refer to "documents... in spoken, written, or graphic forms" (Yang Yann Foo et al., 2021, p. 508) "that exist in a materially replicable form" (Dorothy Smith, 2001, as cited in Grainne Kearney, Michael Corman, Nigel Hart, Jennifer Johnston, & Gerard Gormley, 2019, p. 19) and operate as "mechanisms for coordinating activity across [settings]" (Marjorie DeVault, 2006, p. 294). This includes both texts created in local settings (e.g., documentation) and extra-local settings (e.g., legislation, organizational policies).

The notion of text also includes broader societal **discourses** which are reflected and reinforced through material texts and their use by people. As noted by Marjorie DeVault and Liza McCoy (2002, as cited in Marie Campbell & Frances Gregor, 2002), "discourse refers to a field of relations that includes not only texts and their intertextual conversation, but the activities of people in actual sites who produce them and use them and take

up the conceptual frames they circulate" (p. 40); discourse organizes and is organized by actual people.

**Social relations** refer to "connections among work processes" (Marjorie DeVault, 2006, p. 294) which coordinate activities across space and time (Marie Campbell & Frances Gregor, 2002). Similarly, **ruling relations** refer to the "socially organised exercise of power" (Allyson Ion, 2020, p. 431); they are a "complex of objectified [external and textually-mediated] social relations that organize and regulate our lives" (Dorothy Smith, 1999, as cited in Grainne Kearney et al., 2019, p. 19) from afar.

In Institutional Ethnography, an "**institution**" does not refer to an organization per se, but rather "clusters of text-mediated relations" (Marjorie DeVault & Liza McCoy, 2012, p. 382) "that are organized around a distinctive function, such as... healthcare" (Dorothy Smith, 2005, as cited in Grainne Kearney et al., 2019, p. 19). Although organizations such as hospitals may be known as "institutions" in common language, Institutional Ethnography understands them as organizations that are hooked into the broader institution of healthcare.

## Definitions Related to Peer Support Institutionalization

In this study, I adopt a broad understanding of the term "**peer**." As per Shinjini Bakshi's (2021) definition, a peer is "an equal, or 'someone like me [(or you)],' with shared social or demographic identity and lived experience" (p. 24). Within the scope of this study, "peer" refers to people with shared lived experience of mental health and/or substance use.

**Peer Drift** refers to a process through which peer support workers "[lose] their grounding in peer values and [adopt] more clinical approaches" (Alise de Bie, 2022 p. 725). The World Health Organization (2019) describes some examples of peer drift as "telling peers what they should do instead of listening; focusing on people's diagnoses instead of their recovery; or being uncomfortable or ashamed of one's lived experience and recovery story" (p. 27).

**Institutionalization** refers to "the system-level process by which the [peer support] field gained legitimacy, became embedded within... the mental healthcare system, and expanded" (Wallis Adams, 2020, p. 3). In this study, I use "institutionalization" to refer to the *external* governance of peer support practice through institutional forces shaped by non-peer organizations (e.g., hospital policies, legislation, etc.).

**Professionalization** refers to "a process by which an occupation defines itself as a profession, by establishing appropriate qualifications, regulatory associations, and demarcation from being perceived as unqualified" (Helena Roennfeldt & Louise Byrne, 2021, pp. 1445–1446). In this study, I use "professionalization" to refer to the *internal* governance of peer support

practice by the peer support sector, as well as recommendations from nonpeer organizations that the peer support sector has adopted (e.g., peer support standards, best practices, etc.).

### **CHAPTER 1: BACKGROUND**

#### THE HAMILTON MAD STUDENTS' COLLECTIVE: ENTERING THE WORLD OF PEER SUPPORT

In 2012, I started my undergraduate degree in Psychology at McMaster University. I chose this program out of a desire to better understand my own experiences of "mental health" – and to support others through theirs as well. Unfortunately, I quickly came to realize that this discipline was more interested in labelling and pathologizing experiences like mine, rather than seeking to understand them from the standpoint of those experiencing them. My feelings of exclusion and marginalization did not solely result from the formal curriculum, but my experiences within the classroom as well; I remember handing my academic accommodation letter to one professor, only to have him question whether I would be able to succeed in the course (yes, I could – as long as my accessibility needs were met!).<sup>3</sup> My experiences in school mirrored some of my experiences of pathologization while accessing mental health "care" throughout my undergraduate degree – my doctors seemed to be more interested in medicating me and pointing out the ways in which my thinking was "distorted" than trying to understand and validate the reasons why I felt this way.

However, throughout my degree I came to discover something(s) much more meaningful to me: the language of Madness, the emerging field of Mad Studies, the love of mad community, and the power of peer support. During my first month in the program, I came across a flier for an upcoming meeting of the Mad Students Society (MSS).<sup>4</sup> I was

<sup>&</sup>lt;sup>3</sup> Readers may wonder why I continued in this program despite my negative experiences with/in it. I initially hoped that things would improve in upper year courses. By the time I realized things weren't going to get any better, it felt too late for me to switch programs – I wanted to graduate and leave.

<sup>&</sup>lt;sup>4</sup> In 2014, the Hamilton chapter of MSS branched off to form the Hamilton Mad Students' Collective (HMSC).

intrigued, and longed to connect with others that could understand my experiences more fully – from an experiential standpoint, rather than a clinical standpoint. But I hadn't come across the language of "Madness"<sup>5</sup> before, and I worried that this group wasn't for people like me – people with "mental illness."<sup>6</sup> My initial hesitance toward the group is perhaps best outlined by what I have already written about my experiences, alongside other former members of the Hamilton Mad Students' Collective (HMSC):

The first HMSC meeting I went to, I felt really scared because I didn't know if I belonged. I had never heard of the language of Madness being used in this (reclamatory) way, and I didn't know if this group was meant for people like me (at the time, I had been indoctrinated by medical frameworks of "mental illness"). I walked past the room, peering in, five or six times before I reached for the door. Once inside, I felt intimidated because it seemed like everyone else already knew each other. This discomfort foreshadowed the strong sense of community I came to feel in HMSC; even during my first meeting, I could already recognize the sense of connection between other members (even if I didn't feel these connections myself yet!). Later, someone asked how long the group had been running; I was surprised to find out that this was the very first meeting (see Sayles with de Bie, 2018, for a visual illustration)! I felt like others were also worried about belonging, and that helped me feel less alone... Maybe I could belong here, after all! I found a sense of belonging through our shared feelings of notbelongingness. (Alise de Bie, Chelsea Rothwell, Calvin Prowse, Vaishnavi Yogendran, Meagan Douglass, & Tina Green, 2021, n.p.)

<sup>&</sup>lt;sup>5</sup> By Mad/ness, I refer to and reclaim the politicized and cultural identities of those deemed mentally ill (Erick Fabris, 2013; Stephanie LeBlanc & Elizabeth Kinsella, 2016) and/or in need of mental health treatment (Ameil Joseph, 2013; Jennifer Poole et al., 2012). Inherent in this politicized identity is an awareness of how "mental illness" is constructed, shaped by, and forced upon us through systems of pathologization, social control, and sanism (Erick Fabris, 2013). This framework allows for our connection to and contextualization within: social justice movements, such as the Mad Movement (Alise de Bie, 20202; Stephanie LeBlanc & Elizabeth Kinsella, 2016); the emerging field of inquiry called Mad Studies (Robert Menzies, Brenda LeFrançois, & Geoffrey Reaume, 2013); and a broader history of madness, extending far beyond the invention of psychiatry and the biomedical conceptualization of "mental illness" in the 18<sup>th</sup> century (Stephanie LeBlanc & Elizabeth Kinsella, 2016); Mel Starkman, 2013). The language of Mad/ness resists psychiatric models of mental illness and challenges the legitimacy of psy discourses themselves (Stephanie LeBlanc & Elizabeth Kinsella, 2016). One reason I (now) identify myself with the language of madness is because it allows me to claim and describe this aspect of my identity outside of its relation to psychiatry – unlike terms such as consumer, survivor, mentally ill, etc.

<sup>&</sup>lt;sup>6</sup> Through HMSC, I came to realize how I had been indoctrinated by medical frameworks of "mental illness." I have not identified with the language of mental illness for several years now. However, I use this term here to reflect my use of language at the time.

I became quite involved in HMSC over the next few years, a group which was coordinated by my thesis supervisor, Alise de Bie. While I was initially very quiet, I soon started planning and facilitating meetings. This group introduced me to the power of peer support – when I felt like nobody understood my experiences, my Mad peers did; when my doctor shut down my concerns about my medications, my peers validated them and encouraged my self-determination. I began to feel less alone.

But HMSC offered me more than just support – I learned so much from my peers through our conversations together. We shared secrets – the best places to cry on campus, what academic accommodations were possible at the university, and how to get an incomplete in a class. We explored non-traditional forms of "treatment" together – such as screaming in the woods or hugging a tree. I was also introduced to alternative frameworks through which to understand my experiences – the language of madness and disability, which positioned my experiences of madness as a form of (neuro)diversity deserving of (and legally entitled to) accommodation; and the language of sanism and ableism, which understood my experiences of mistreatment as forms of discrimination and oppression, instead of mere "stigma."

I began to cast off the shame that I had been carrying, as I came to understand it as a form of internalized sanism. As it turns out, this shame was a big part of the distress I had been feeling! Through these experiences, I learned that peer support had much more to offer than just "support" – it was also a way to share knowledge, and generate new knowledge held in community. Some of this knowledge we shared outside the group, through creating zines together;<sup>7</sup> other things we kept to ourselves.

<sup>&</sup>lt;sup>7</sup> The second issue of the Mad Pride Hamilton zine, *This Insane Life*, focused on the experiences of Mad students, is available through MacSphere: <u>https://macsphere.mcmaster.ca/handle/11375/25051</u>

It was also through HMSC that I came immerse myself within the emerging field of Mad studies – both by "doing" Mad studies by organically engaging with/in mad community, and through an independent Mad Studies course arranged by my thesis supervisor, Alise de Bie. I was drawn to this field both by its critical perspectives of "mental health" and the psy professions, and in how it centred mad peoples' experiences and knowledges in this work – I was tired of "professionals" defining our experiences for us!

I was excited to share some of the things I had learned with the world, and hopefully create changes in how "mental health" was understood and responded to on campus and beyond. In 2014, alongside my HMSC peers, I co-presented at a peer support conference hosted by the Ontario Peer Development Initiative (OPDI) and provided training to teaching assistants at McMaster University on how to facilitate a "mad positive" classroom. In 2016, I participated in a panel discussion for McMaster's *Mental Health & Intersectionality Conference* hosted by COPE: A Student Mental Health Initiative, where I discussed the intersections between queer and mad identity. In these presentations, I shared about the value of peer support, and the alternative frameworks I came to know about through my immersion in HMSC and the field of Mad studies.

#### UNCOVERING A TRIANGLE MODEL OF PEER WORK

In 2020, I had the opportunity to gather with several other former HMSC members to reflect on our experiences and to mourn the loss of HMSC.<sup>8</sup> We wrote about our experiences so that we could "leave evidence" of HMSC – "that we were here, that

<sup>&</sup>lt;sup>8</sup> In 2016, advocacy from HMSC members and other disabled students led to the creation of MSU Maccess, a peer support service for disabled, chronically ill, and mad students at McMaster. Around this time, HMSC became less active, and eventually, meetings stopped altogether.

we existed, that we survived and loved and ached" (Mia Mingus, n.d., n.p.). Through our conversations, I came to discover one of the reasons why HMSC felt so meaningful to me – the ways in which elements of caring about one another, sharing and creating knowledge together, and working toward change felt deeply intertwined and inseparable:

Mourning the loss of [the Hamilton Mad Students Collective] ... has helped me reflect on the interdependence of Mad ways of caring ... knowing ... and change-making ... The interconnectedness of these three areas, like the points on a triangle, have become a core part of my Mad praxis (Alise de Bie et al., 2021, n.p.)

I came to refer to this as a "triangle model of peer work," recognizing the ways in which these elements supported and strengthened one another. This framework assumes that peer work of all kinds relies on care, knowledge, and change functions in varying levels, and that these functions are interdependent: care, knowledge, and change work support and strengthen one another, promoting synergy (Calvin Prowse, 2021b).



Figure 1: A Triangle Model of Peer Work

I conceptualize peer support as an act of caring *about* (Anne Scott & Carolyn Doughty, 2012a) which draws on experiential knowledge (Helena Roennfeldt & Louise Byrne, 2021) and works toward social and systems change, in line with its social movement origins (Anthony Stratford, Matt Halpin, Keely Phillips, Frances Skerritt, Anne Beales, Vincent Cheng, Magdel Hammond, Mary O'Hagan, Catherine Loreto, Kim Tiengtom, Benon Kobe, Steve Harrington, Dan Fisher, & Larry Davidson, 2019). I experienced these elements in HMSC as we supported one another, shared and (co-)created knowledge, and worked to shift conversations on campus (and beyond) from "mental illness" to "madness."

### PEER SUPPORT TRAINING: AN ENTRY POINT TO PEER SUPPORT AS A "PROFESSION"

In 2014, myself and other members of HMSC completed peer support training through a local consumer/survivor initiative, the Mental Health Rights Coalition

(MHRC).<sup>9</sup> Through this training, I came to understand peer support as a profession – not just something I could do with my friends and within my communities, but something I could actually do for a career! I started taking other trainings related to peer support, and when I completed my courses in 2016, I began to look for a job in peer support.

I didn't have much luck in my job search, and I began to realize how few peer support positions existed in my community. Although I did have a few interviews, I never received any offers for employment. I began to notice that some peer support positions required or preferred post-secondary education in a related field – one job description that I looked at required a "Psychosocial Rehabilitation Certificate, Social Service Worker Diploma, or a degree or diploma in a social-services or health-related field." Although I applied thinking that my psychology degree would meet this requirement, I didn't get an interview – I began to wonder if this was because my psychology degree was not practically-oriented, and/or because I didn't have experience working in clinical environments.

After being out of school for two years, working a retail job that left me living paycheck-to-paycheck, I hit a stroke of luck: in 2018, I found out that I had been selected for the Ontario Basic Income Pilot program,<sup>10</sup> through which I would receive monthly payments for the next three years. Now that I didn't have to worry as much about paying my bills, I began to entertain the idea of returning to school. I discovered that McMaster

<sup>&</sup>lt;sup>9</sup> Many thanks to Alise de Bie for coordinating this training session for us.

<sup>&</sup>lt;sup>10</sup> The Ontario Basic Income Pilot provided an unconditional income to approximately 4,000 low-income people in the communities of Hamilton/Brantford/Brant County, Lindsay, and Thunder Bay. Individuals received up to \$16,989 a year, with increased rates provided to couples and people with disabilities. Payments were reduced by 50 cents per dollar earned through employment. The pilot program was intended to study the effects of a basic income and was planned to last three years. (Tom McDowell & Mohammad Ferdosi, 2021)

had a "post-degree" Bachelor of Social Work (BSW) program; because I had already completed my BA, I was able to "fast-track" my BSW and graduate in two years, instead of the typical four – just enough time for me to finish my degree before my basic income payments would stop. I applied to the program and was accepted.

I chose to return to McMaster for my BSW for several reasons. I hoped that this degree would make me more qualified for peer support roles, both through the degree itself and the two mandatory placements of the BSW which would allow me to gain some of the "work experience" I felt I was missing. Through HMSC, I had met several Mad students in the social work department – it sounded like I would experience much less sanism/ableism in this department, and even if I did, at least I had some friends there! I had already spent a significant amount of time in the social work building, which became a regular meeting spot for HMSC. I felt like professors in the department might be more knowledgeable about peer support, the language of madness, and Mad studies – and that they might be more supportive of Mad students than my psychology professors were.

The 2018 Ontario election resulted in a Conservative majority government led by Premier Doug Ford. In July of 2018 (Tom McDowell & Mohammad Ferdosi, 2021), despite numerous promises to the contrary during their campaign, the newly-elected government announced the cancellation of the Ontario Basic Income Pilot – less than a year after it had begun.<sup>11</sup> I was weeks away from starting classes, and from giving my job my two-weeks notice. Suddenly my plans were thrown off course; I had no idea if I could afford to leave my job and return to school without basic income payments. I decided to

<sup>&</sup>lt;sup>11</sup> Although the government announced the cancellation of the Ontario Basic Income Pilot in August of 2018, participants continued to receive payments until March 29, 2019 (Tom McDowell & Mohammad Ferdosi, 2021). However, when the cancellation was initially announced, there was no indication of when payments would stop – leaving participants in a state of uncertainty.

press forward and return to school – working part-time at the university to help pay my bills, and taking three years to complete my BSW instead of the anticipated two.

### AN ENTRY POINT TO INSTITUTIONALIZED PEER SUPPORT

Throughout my BSW degree, I was required to complete two placements, which I used to deepen my knowledge and practice of peer work. In 2019, I began my first placement at a youth mental health agency managed by a hospital. However, instead of working as a (student) social worker, I was able to complete my placement in the role of a peer support worker. I was excited for the opportunity to deepen my knowledge and explore peer support within a more formal healthcare environment – as opposed to the more grassroots peer support initiatives I had been involved with up to that point.

One challenge I experienced in the shift toward providing peer support in a formal environment was around writing documentation – something I had never done before, or at least in the way it was required in this setting.<sup>12</sup> Although I initially thought the difficulty I faced writing documentation was because I did not have experience doing so, I came to realize how my discomfort was related to tensions I felt between peer values, consumer/survivor movement histories, and documentation practices.

I felt tensions between expectations of documentation and peer values – namely, the value of self-determination, which I felt was compromised when I framed my peers' experiences on their behalf. I also thought about the history of the psychiatric consumer/survivor movement, from which peer support emerged – which developed in

<sup>&</sup>lt;sup>12</sup> Alise drew my attention to the (different) ways that we engaged in "documentation" in HMSC. We used a confidential 24/7 listserv to post meeting topics, and through which members could write posts and respond to one another. Although our meetings and interactions with one another were "documented," this was a very different approach to documentation than in healthcare settings – where one person (the service provider) writes notes about another person (the service user).

response to mistreatment by mental health organizations and the power that professionals hold over the lived of people deemed "mentally ill." Conventional documentation practices give professionals the power to name and frame our (peers') experiences and direct what our "care" looks like.

I navigated some of these tensions through discussions with my placement (peer) supervisors, who referred me to a document describing guidelines for peer support documentation.<sup>13</sup> I found this resource to be quite helpful; however, I noticed that some of the suggestions<sup>14</sup> came from research conducted by Anne Scott and Carolyn Doughty (2012b) on how peer support workers in Aotearoa (New Zealand) approach the work of documentation. I noticed that although Anne Scott and Carolyn Doughty discuss peer supporters' approaches to documentation as a response to neoliberal pressures for documentation (which I understand as a form of subversive resistance to institutional demands for surveillance), the authors of the guidelines provided no mention of their original subversive intents.

I wrote about this "felt trouble" (Allyson Ion, personal communication, 2022) for my placement seminar class, and later developed a webinar for OPDI about the tensions inherent in peer support documentation (Calvin Prowse, 2021a). In my webinar, I

<sup>&</sup>lt;sup>13</sup> I have chosen not to cite this document for several reasons. First, the guidelines which I referred to have since been updated, and the version I consulted is no longer publicly available online; the updated version no longer references the research of Anne Scott and Carolyn Doughty (2012b). Second, I do not wish to speak poorly of the organization that developed these guidelines; in fact, I found these guidelines quite helpful for working through my challenges and concerns with documentation. My critique is not about the agency itself, but rather how these guidelines did not adequately contextualize recommendations within broader processes of institutionalization.

<sup>&</sup>lt;sup>14</sup> Anne Scott and Carolyn Doughty (2012b) noted that peer supporters in their study described "keeping minimal information about their interactions with peers, or keeping notes in a collaborative, empowering and transparent manner" (p. 154). Although they note that these approaches were a form of "challeng[ing] disciplinary uses of documentation" (p. 154) within contexts where it was required, this explanation was ommitted from the guidelines; instead, they were presented as recommendations for how peer support workers should approach the work of documentation.

explored how these guidelines oriented peer supporters toward the everyday work of documentation in particular ways, while obscuring cautions (raised by Anne Scott and Carolyn Doughty) about the impact of documentation on peer support values. The purpose of this webinar was to encourage peer support workers to approach their documentation work in a critical way.

Navigating this tension with documentation expectations was one of my entry points to the problematization of peer support professionalization and institutionalization.<sup>15</sup> Although peer support workers can be paid for providing peer support within mainstream settings, we are also required to adopt institutional practices and perspectives (like documentation), which often operate through a medical model that prioritizes the knowledges and perspectives of clinical professionals over those of peers and the field of peer support. Although I am pleased that peer support is becoming more widely known and available, giving folks with mental health concerns another avenue to explore for support, I worry that practices associated with institutionalization might erode our peer values and result in peer drift.

In 2021, I began my Master of Social Work (MSW) degree at McMaster University. Although presumably my BSW would have met my initial reasons for returning to school (to become more employable in the peer support sector), I did not feel safe entering the (in-person) "work force" during the COVID-19 pandemic. At the same time, I still had more questions about peer support, and I hoped that my MSW research would provide an opportunity for me to continue to explore them. My experiences feeling

<sup>&</sup>lt;sup>15</sup> My research originally intended to explore the impacts of peer support professionalization, not institutionalization. However, processes of professionalization and institutionalization are deeply intertwined (Trish Reay et al., 2016), and throughout my research I came to discover that my findings spoke more closely to processes of institutionalization than professionalization.

troubled by documentation requirements led me to explore the institutionalization of peer support and formed the problematic of my MSW research study. I wondered how processes of institutionalization and professionalization shaped the everyday work of peer support, and how these practices (mis)align with peer values and histories. I wondered if (and how) these practices can contribute to peer drift, and a co-option of peer support as both a practice and way of knowing.

#### **CHAPTER 2: PEER SUPPORT HISTORY & SOCIAL MOVEMENT ORIGINS**

Before starting my research, I needed to complete a literature review. Although I was already familiar with a broad range of peer support literature due to my peer support practice and previous academic exploration of peer support work, I had to piece together how the literature connected to my research topic.

I chose to focus on reviewing the historical context of peer support within the psychiatric consumer/survivor movement. Helena Roennfeldt and Louise Byrne (2021) note that professionalization could lead to the erosion of peer support values; as such, literature often stresses the importance of peer supporters being educated on the social (movement) and historical context of peer support, from which peer support values emerged (Anthony Stratford et al., 2019; Kim Sunderland, Wendy Mishkin, Peer Leadership Group, & Mental Health Commission of Canada , 2013). I felt that a historical review would provide a helpful context for this study and allow for a preliminary consideration of if or how institutionalized peer support aligns with its historical roots. In this literature review, I draw on academic literature and grey literature, as well as Judi Chamberlin's (1978/2012d) book *On Our Own*. Following a brief overview of the origins of the consumer/survivor movement, I explore the discourses of care, knowledge, and empowerment within this history.

#### **CONSUMER/SURVIVOR MOVEMENT ORIGINS**

## Early Mental Patient Organizing

Stories of the history of mental health-focused peer support often begin with its origins in the psychiatric consumer/survivor movement in Canada and the US following

13

#### MSW Thesis – Calvin Prowse

deinstitutionalization<sup>16</sup>. However, this timeline paints an incomplete picture, as mental patient organizing and self-help strategies can be traced back even further. In the 1860s, Elizabeth Packard was committed to an asylum in Illinois for three years by her husband, because she questioned his religious views and support for slavery (Geoffrey Reaume, 2002). She later published about her experiences of incarceration<sup>17</sup>, founded the Anti-Insane Asylum Society, and advocated for legislative reform to prevent women from being committed solely on account of their husbands' testimony (Judi Chamberlin, 1990; Geoffrey Reaume, 2002). In England, the Alleged Lunatics' Friend Society was created by ex-patients in 1845 (Judi Chamberlin, 1990) to advocate for legislative change and expose mistreatment within asylums (Nicholas Hervey, 1986; John Perceval, 1851). I raise these histories to contextualize the consumer/survivor movement within a larger and longer legacy of ex-patient mobilizing. However, Judi Chamberlin (1990) notes that expatient groups emerged in the 1970s without knowledge of this history.

#### **Deinstitutionalization**

Psychiatric deinstitutionalization in Canada and the US began during the 1960s and paved the way for the consumer/survivor movement to emerge (Barbara Everett, 1994). Deinstitutionalization brought forward the idea that mad people did not require indefinite confinement in asylums, but rather could return to living in the community (Barbara Everett, 1994). Under this discourse, the domain of mental health treatment shifted from institutional to community-based care (Marina Morrow, 2013; Helena

<sup>&</sup>lt;sup>16</sup> For example: Wallis Adams, 2020; Geertje Boschma & Courtney Devane, 2019; Jean Campbell, 2005; Anne Scott & Carolyn Doughty, 2012a, 2012b; and Anthony Stratford et al., 2019.

<sup>&</sup>lt;sup>17</sup> Here, I use the language of "incarceration" to exemplify how Elizabeth Packard understood her experiences of being confined to an asylum as similar to those faced by people in prisons (Geoffrey Reaume, 2002).

Roennfeldt & Louise Byrne, 2021); hospitalization was reframed as a temporary measure which was only needed for brief periods of stabilization (Barbara Everett, 1994). Materially, deinstitutionalization resulted in two-thirds of psychiatric beds in Canada being closed over a 16-year period (G. F. Heseltine, 1983, as cited in Barbara Everett, 1994), with ex-patients sent back into the community, often without adequate supports (Helena Roennfeldt & Louise Byrne, 2021; Nancy Tomes, 2006) such as housing and financial assistance (Barbara Everett, 1994; Helena Roennfeldt & Louise Byrne, 2021; Nancy Tomes, 2006).

The deinstitutionalization movement was influenced by a variety of discursive and material contexts. Discursively, deinstitutionalization was shaped by the government's desire to reduce the financial costs of the mental health system, as well as an increased attention to human rights as a result of the civil rights movement (Barbara Everett, 1994; Geoffrey Reaume, 2002). Materially, deinstitutionalization was enabled by the development of neuroleptic drugs which promised to "cure" mental illness and allow expatients to re-join life in the community (Barbara Everett, 1994; Geoffrey Reaume, 2002).

Deinstitutionalization created a context in which Mad people were enabled to organize; being freed from the forced intimacy of asylums allowed them to join together in protest on their own terms (Barbara Everett, 1994). In Canada, early ex-patient groups included the Mental Patients Association in Vancouver, founded in 1971, and the Ontario Mental Patients Association (later renamed On Our Own) in Toronto, founded in 1977 (Judi Chamberlin, 1990; Ameil Joseph, 2013).

15

## DISCOURSES OF CARE, KNOWLEDGE, AND EMPOWERMENT IN CONSUMER/SURVIVOR MOVEMENT HISTORIES & SELF-HELP ALTERNATIVES

Below, I trace three discursive threads of the psychiatric consumer/survivor movement, and their implications for peer support philosophy and practice: notions of "care," experiential knowledge, and empowerment/emancipation. This focus aligns with a triangular(izing) epistemology<sup>18</sup> which focuses on the interconnections between elements of caring, knowing, and change-making in peer support practice. In discussion of these three threads, I outline how discourses of care, experiential knowledge, and empowerment/emancipation are influenced by and intertwined with feminist movements, the gay liberation movement, anti-psychiatry, the civil rights movement, disability rights movement, and broader self-help movements.

Before discussing the consumer/survivor movement as a whole, it is necessary to highlight the ideological differences between psychiatric consumer and survivor perspectives. Indigo Daya, Bridget Hamilton, and Cath Roper (2020) note that "experiences of treatment and care can influence different language preferences" (p. 305) and shape both discourse and advocacy priorities – these differences are reflected in the terms "consumer" and "survivor." However, it is important to note that Indigo Daya et al. (2020) understand these as discursive categories which may not necessarily reflect the language people use to self-identify (Indigo Daya et al., 2020).

Consumer discourse draws on the notion that mental patients are "consumers" of the mental health system and are therefore entitled to choice and control over the services they use, drawing on broader discourses of "consumers' rights" (Geoffrey Reaume, 2002;

<sup>&</sup>lt;sup>18</sup> This triangular(izing) epistemology will be further described in <u>Chapter 5 – Triangular(izing)</u> <u>Epistemology.</u>

Nancy Tomes, 2006). Consumers draw on a rights discourse (Barbara Everett, 1994) and adopt a reformist agenda by working to improve the mainstream mental health system (Indigo Daya et al., 2020). This discourse shapes how consumers interact with professionals and their approach to change. Consumers are more likely to engage with professionals, and work towards reform with/in the system through advocating for their inclusion in decision-making processes (Barbara Everett, 1994). In fact, Judi Chamberlin (1990) suggests that consumers' adoption of a reformist agenda may have been a *result* of their engagement with non-patients, who rapidly took on leadership roles and shaped priorities to better reflect their perspectives.

On the other hand, the term "survivor" refers to surviving oppression and psychiatric abuse, reframing psychiatrization as a source of harm (Geoffrey Reaume, 2002).<sup>19</sup> Survivors draw on broader liberation discourses and work towards liberation from psychiatric control (Barbara Everett, 1994). Survivors tend to reject the medical model of mental illness and adopt an antipsychiatry approach (Alexandra Adame, 2014); as such, they are oriented toward operating independently from professionals, working to create change from outside of the system (Barbara Everett, 1994). They are more likely to reject mainstream services, and instead advocate for psychiatric abolition and independent peer-run services (Indigo Daya et al., 2020).

Taking these discursive differences to the extreme, Everett (1994) notes that "survivors feel that consumers are dupes for believing that the mental health system has

<sup>&</sup>lt;sup>19</sup> Since the mid 1990s, people have started to use the language of "survivor" to self-identify as surviving mental illness, as opposed to psychiatry (Geoffrey Reaume, 2002). This reflects a new form of survivor discourse, which, although worth noting, is not the discourse I refer to in my review of consumer/survivor movement histories in this chapter, which is largely focused prior to the 1990s. This discourse may be more applicable to Chapter 3, which focuses on the professionalization and institutionalization of peer support during the 1990s and beyond.

any value at all... [whereas] consumers believe that there is no shame in working for change from within the system" (p. 63), highlighting the differences between these two perspectives of the psychiatric system and approaches toward social change.

### Part 1 – Critiquing (& Redefining) "Care"

The consumer/survivor movement arose in response to harmful "care" practices. For example, scholars have described contexts of psychiatric abuse (Barbara Everett, 1994), coercion (Anne Scott & Carolyn Doughty, 2012b), and dehumanization (Jean Campbell, 2005), enabled by extreme power imbalances within the psychiatric system. In addition, a lack of available supports following deinstitutionalization left mad people to "fend for themselves" (Nancy Tomes, 2006, p. 724), leading them to seek out one other for support.

Experiences in medical care are often dehumanizing and marked by professional detachment (Jean Campbell, 2005). However, patients have noted the value of personal contact, communication, and concern, reflecting a preference for humanizing care interactions and the importance of the "therapeutic relationship" (Jean Campbell, 2005). Judi Chamberlin (1978/2012c) notes that mental health professionals' goals of "detachment and impartiality... become, in practice, either cold formality or the shallow pretense of friendliness" (p. 149); in other words, "care" is often experienced by mental health service users as inauthentic and anything but caring. However, patients have noted the value of personal contact, communication, and concern, reflecting a preference for humanizing care interactions and the importance of the "therapeutic relationship" (Jean Campbell, 2005).
Deinstitutionalization resulted in ex-patients being released back into the community en masse (Geoffrey Reaume, 2002), but left them isolated, lonely, and lacking meaningful relationships (Jean Campbell, 2005). Consumer/survivors began to seek each other out for validation and support, outside of the confines of the psychiatric system (Jean Campbell, 2005). Instead, the consumer/survivor movement advocated for and created self-help alternatives to the mental health system, through which ex-patients could support one another in community (Jean Campbell, 2005).

Jean Campbell (2005) notes that "caring functions are the foundation of individual mutual support and reflect the need for empathetic services and supports in response to social isolation and the failures of the community mental health system" (p. 34). To redress the power imbalances of the psychiatric system, peer support draws on the value of mutuality, shifting discourses of care from paternalistic notions of "caring *for*" others toward a mutual form of "caring *about*" each other (Anne Scott & Carolyn Doughty, 2012a).<sup>20</sup>

Shery Mead, David Hilton, and Laurie Curtis (2001) describe peer support as an "expansion of community... [as opposed to] professionalized caretaking of people defined as defective" (p. 136), and define "recovery" as "undoing the cultural process of developing careers as 'mental patients'... by practicing relationships in a different way" (p. 135-136). This positions peer support as a relationship-based practice (Helena Roennfeldt & Louise Byrne, 2021) oriented toward social connection, community, wellness, and strengths – as opposed to symptoms, problems, "illness," and deficit (Shery Mead et al., 2001; Helena Roennfeldt & Louise Byrne, 2021). The discourse of mutuality

<sup>&</sup>lt;sup>20</sup> As noted by Anne Scott and Carolyn Doughty (2012a), peer support literature typically uses the language of "support" instead of "care," in order to distance itself from paternalistic notions of caring-for.

shapes the practices of peer support workers toward developing trusting relationships and centreing the self-determined goals of their peers, by embracing a "responsibility *towards*" (rather than *for*) their peers (Anne Scott & Carolyn Doughty, 2012a).

# Part 2 – Consciousness-Raising & Experiential Knowledge

The consumer/survivor movement was influenced by women's and gay liberation movements which critiqued psychiatry and resisted psychiatrization (Judi Chamberlin, 1990; Mel Starkman, 2013). The medical model frames madness as pathology and disease with biological origins, obscuring the role of oppression and social factors in experiences of madness (Shery Mead et al., 2001; Jennifer Poole, Tania Jivraj, Araxi Arslanian, Kristen Bellows, Sheila Chiasson, Husnia Hakimy, Jessica Pasini, & Jenna Reid, 2012). It positions mad people as "in need of… treatment, cure, or regulation" (Helen Meekosha & Leanne Dowse, 2007, as cited in Jennifer Poole et al., 2012, p. #), providing professionals with the authority to define our experiences (Marina Morrow, 2013) and decide what is in our best interests on our behalf (Jennifer Poole et al., 2012). Many mad people internalize these medical model frameworks and adopt mental patient roles (Shery Mead et al., 2001), through which we learn to doubt our own judgement and submit to psychiatric "expertise": we learn to be dependent, and that we have nothing to offer (Judi Chamberlin, 1978/2012a).

Under the rule of the psychiatric system, professional knowledges subjugate experiential knowledges (Alison Faulkner, 2017); as Judi Chamberlin (1978/2012a) notes, "staff members don't believe what patients tell them" (p. 6). Mad people's knowledge is regularly dismissed and discredited (Judi Chamberlin, 1978/2012a), which Stephanie LeBlanc and Elizabeth Kinsella (2016) identify as a form of testimonial

epistemic injustice: the discrediting of Mad people as legitimate knowers. We are assumed to "lack insight" and to not know what is in our own best interests (Jean Campbell, 2005; Judi Chamberlin, 1978/2012a), enabling professionals to take responsibility over us and our care. Additionally, mad people experience hermeneutical epistemic injustice when the dominance of psychiatric discourses makes it difficult to communicate or understand our experiences differently as a result of a lack of alternative interpretive frameworks (Stephanie LeBlanc & Elizabeth Kinsella, 2016).

The consumer/survivor movement drew on feminist consciousness-raising practices (Mel Starkman, 2013) which enabled ex-patients to share their experiences with one another and understand them within a larger socio-political context (Shery Mead et al., 2001). Consciousness-raising led ex-patients to coin the term "mentalism"<sup>21</sup> (Judi Chamberlin, 1978/2012b, p. 66), also known as sanism (Jennifer Poole et al., 2012), providing a framework through which to understand their experiences of mistreatment as a form of oppression. This emphasis on experiential knowledge positioned mad people as the experts of our own lives and experiences, while simultaneously challenging professional knowledges (Alison Faulkner, 2017).

Consumer/survivors shared their knowledges with one another and the general public through various self-published newsletters such as *In a Nutshell* (Vancouver, Mental Patients Association, starting in 1972), *Madness Network News* (California, 1972–

<sup>&</sup>lt;sup>21</sup> Judi Chamberlin is sometimes credited as coining the term "mentalism" (for example: Stephanie LeBlanc & Elizabeth Kinsella, 2016). However, in *On Our Own*, Judi Chamberlin (1978/2012b) does not take credit for coining the term herself (although her book likely facilitated wider use of the term). Instead, she notes that "negative stereotypes of the 'mentally ill'... ha[ve] been termed 'sane chauvinism' or mentalism' *by mental patients*' *liberation groups*" (p. 66, emphasis added).

1986), and *Phoenix Rising: The Voice of the Psychiatrized* (Toronto, 1980–1990; Geoffrey Reaume, 2002).

The discourse of experiential knowledge positioned peers as having "special insight into mental disease by having actually experienced it" (Nancy Tomes, 2006, p. 722). Peer support is positioned as a "lived experience-based" practice (Helena Roennfeldt & Louise Byrne, 2021, p. 1447), through which peers draw on our experiential expertise to support others (Wallis Adams, 2020). Our experiential knowledge is further deepened when it is based not only on personal lived experience, but also from knowledge generated in community by passing down knowledge and sharing stories with one another (Alison Faulkner, 2017) through peer support consciousnessraising practices.

#### Part 3 – Empowerment & Emancipation

Around the same time as deinstitutionalization, a discourse of anti-psychiatry was brought forward by scholars and professionals such as Erving Goffman, Thomas Szasz, Michel Foucault, and R. D. Laing, who critiqued the concept of "mental illness" and the power relations inherent in psychiatrization (Geoffrey Reaume, 2002). Nancy Tomes (2006) suggests that the discourses of the early psychiatric survivor movement were heavily influenced by the anti-psychiatry movement, which led the movement to reframe madness as an alternative state of being as opposed to an illness. However, relationships between psychiatric survivors and anti-psychiatrists were tenuous; Judi Chamberlin (1990) notes that "there [was] little attempt within anti-psychiatry to reach out to struggling ex-patients or to include their perspective" (p. 324). Psychiatric care is rife with power imbalances, which allow professionals to decide that patients are incapable of determining their own best interests, and to commit them to an institution for treatment against their will (Judi Chamberlin, 1990). Drawing on the work of Thomas Szasz, Judi Chamberlin (1978/2012a) notes that institutional psychiatrists are accountable not to their patients, but to those who want patients locked up (the state, family, friends, etc.).

Barbara Everett (1994) suggests that one goal of the consumer/survivor movement is to "expose and critique the power relations" (p. 67) of the psychiatric system. In addition to anti-psychiatry perspectives, the consumer/survivor movement was also influenced by the rights-based frame of the civil rights movement (Jean Campbell, 2005), and discourses from the disability rights movement which emphasized the value of choice as a form of resistance to paternalist models of caring-for (Anne Scott & Carolyn Doughty, 2012a). This material and discursive context paved the way for the consumer/survivor movement to adopt a discourse of emancipation, emphasizing human rights and choice.

In practice, the consumer/survivor movement advocated for the right to choose – and refuse – treatment (Shinjini Bakshi, 2021; Judi Chamberlin, 1990), reframing involuntary treatment from a form of "help" to a violation of human rights (Barbara Everett, 1994). The movement leveraged discourses of empowerment to advocate against forced treatment (Anne Scott & Carolyn Doughty, 2012a), inform patients of their rights, and work to change laws related to commitment to institutions (Judi Chamberlin, 1978/2012a). In 1985, as a result of advocacy efforts from On Our Own and the Advocacy Resource Centre for the Handicapped, people in mental institutions gained the right to vote in Ontario political elections (Geoffrey Reaume, 2003).

Barbara Everett (1994) suggests that one goal of the consumer/survivor movement is to "create symbolic change enroute to real change" (p. 63). Embracing the South African disability rights motto "Nothing About Us, Without Us," consumers sought their inclusion and partnership in mental health policy, practice, and research (Nancy Tomes, 2006), drawing on their lived experience as a tool of system reform.

But the consumer/survivor movement did more than critique and reform the mental health system – another goal of the movement was to establish self-help alternatives (Barbara Everett, 1994). The movement was influenced by the rise of self-help strategies in other settings (Jean Campbell, 2005), through which "people began to take power back from the professionals" (Mel Starkman, 2013, p. 29). From this context, and in response to psychiatric coercion (Anne Scott & Carolyn Doughty, 2012b), peer support emerged with a discursive focus on empowerment (Jean Campbell, 2005) and the related terms of choice, self-determination, and socio-political emancipation (Anne Scott & Carolyn Doughty, 2012a). Empowerment has been described as "having the right to make one's own health care choices" (Nancy Tomes, 2006, p. 720); in practice, peer support.

# **CHAPTER 3: PROFESSIONALIZATION & INSTITUTIONALIZATION**

In addition to providing a historical context of peer support within the psychiatric consumer/survivor movement, I also wanted to explore how the field of peer support found its way to its current state of working to be recognized as a profession, while becoming increasingly institutionalized within mainstream mental health settings. In this chapter, I describe key moments that furthered the professionalization and institutionalization of peer support in Ontario, and explore current trends and troubles relating to the institutionalization of peer support within mainstream healthcare settings.

### PEER PROFESSIONALIZATION AND INSTITUTIONALIZATION IN ONTARIO, CANADA

Following a brief introduction to the processes of professionalization and institutionalization, I discuss key moments through which these processes emerged for peer support in Ontario and Canada: (1) the creation of the Consumer/Survivor Development Initiative (CSDI), (2) the publication of *Making the Case for Peer Support* (Céline Cyr, Heather Mckee, Mary O'Hagan, & Robyn Priest, 2010, second edition 2016) and *Guidelines for the Practice and Training of Peer Support* (Kim Sunderland et al., 2013) by the Mental Health Commission of Canada (MHCC), and (3) the formation of Peer Support Canada as a national peer support accreditation body.

## Defining Professionalization and Institutionalization

Professionalization and institutionalization are two distinct, yet highly intertwined processes. Helena Roennfeldt and Louise Byrne (2021) define professionalization as "a process by which an occupation defines itself as a profession, by establishing appropriate qualifications, regulatory associations, and demarcation from being perceived as unqualified" (pp. 1445-1446), whereas Wallis Adams (2020) describes the

institutionalization of peer support as "the system-level process by which the field gained legitimacy, became embedded within... the mental healthcare system, and expanded" (p. 3). Put simply, professionalization occurs when an occupation begins to be viewed *as* a profession which requires certain qualifications and skills, whereas institutionalization refers to becoming embedded within institutions – in the case of peer support, often within healthcare insitutions.

In practice, processes of professionalization and institutionalization are interdependent and mutually reinforcing. Helena Roennfeldt and Louise Byrne (2021) note that "the growing interest in lived experience as a profession has arisen in part as a response to embedding [or institutionalizing] the lived experience workforce within mainstream services" (p. 1447), which are both highly institutionalized and professionalized (Trish Reay, Elizabeth Goodrick, & Bob Hinings, 2016). However, tensions emerge when professionalizing peer support within mainstream settings which prioritize formal education, as peer support is based on relationships and experiential knowledge ((Helena Roennfeldt & Louise Byrne, 2021).

To gain legitimacy within mainstream settings, peer support may be forced to adapt to institutional demands for formal knowledge, resulting in a decreased emphasis on experiential knowledge – the very heart of peer support. Through institutionalization, peer support becomes further professionalized, by necessity; peer supporters work to meet institutional demands for formal knowledge through gaining qualifications, such as through peer support certification processes. Helena Roennfeldt and Louise Byrne (2021) note that lived experience roles such as peer support currently have a "liminal occupational identity" (p. 1450) that is somewhat, yet not fully professionalized.

## The Consumer/Survivor Development Initiative (CSDI)

In 1991, the Ontario government began systematically funding consumer/survivor initiatives (CSIs) through the Consumer/Survivor Development Initiative (CSDI; later renamed the Ontario Peer Development Initiative, OPDI),<sup>22</sup> although small amounts of funding had been provided to organizations prior (John Trainor, Marnie Shepherd, Katherine Boydell, Allyson Leff, & Elaine Crawford, 1997). To receive funding through CSDI, CSIs were required to be independent from mainstream services, and were not permitted to replicate traditional client/provider service paradigms; rather, they were intended to develop new models grounded in mutuality and collectivity (John Trainor et al., 1997).

In 1996, the Ministry of Health became concerned by the organizational difficulties faced by CSIs and their departure from the organizational styles of traditional services. Instead of providing support to CSIs to work through organizational challenges, the Ministry of Health removed the requirement of autonomy from mainstream services (Geoffrey Nelson, Rich Janzen, John Trainor, Joanna Ochocka, 2008). Over 40 autonomous initiatives emerged during the 1990s, but today, only a few remain independent (Alise de Bie, 20220).

While reviewing this history, I came to understand the creation of CSDI as a key turning point toward peer support professionalization in Ontario – a time when the government recognized the value of peer support and CSIs, and began investing in them through providing systematic funding. Drawing on Helena Roennfeldt and Louise Byrne's (2021) definition of professionalization, the government's decision to fund CSIs

<sup>&</sup>lt;sup>22</sup> More recently, OPDI announced the decision to rename the organization PeerWorks during the OPDI Annual General Meeting on October 6, 2022.

through CSDI enabled peers to be understood as qualified by virtue of their lived experience. Additionally, I came to understand the removal of independence requirements to be a key turning point toward institutionalization, which enabled peer support to "become embedded within the official administrative structures of the mental healthcare system" (Wallis Adams, 2020, p. 3).

### The Mental Health Commission of Canada & Peer Support Canada

More recently, the Mental Health Commission of Canada (MHCC) has commissioned several reports on peer support, including *Making the Case for Peer Support* (Céline Cyr et al., 2016; first edition released in 2010) and *Guidelines for the Practice and Training of Peer Support* (Kim Sunderland et al., 2013). In addition, this work by the MHCC resulted in the development of Peer Support (Accreditation and Certification) Canada, a national accreditation body for peer support workers (Geertje Boschma & Courtney Devane, 2019). I outline the trajectory of this development below.

In 2010, an advisory committee was developed by the MHCC to "provide guidance on how to strengthen [institutionalized] peer support programs across Canada" (Geertje Boschma & Courtney Devane, 2019, p. 91), with the goal of "fully integrat[ing] peer support within Canada's mental health system" (Peer Support Canada, 2022, p. 6). This led to the publication of *Making the Case for Peer Support* (Geertje Boschma & Courtney Devane, 2019). In addition, this advisory committee created Peer Support Accreditation and Certification Canada (PSACC), which "established a framework involving standards of practice, core values and principles to guide peer support workers" (Peer Support Canada, 2022, p. 6).

In 2017, PSACC became a program of the national branch of the Canadian Mental Health Association (CMHA National) and was renamed Peer Support Canada (Peer Support Canada, 2022). Peer Support Canada offers national certification for peer support workers at a total cost of \$1,280, which takes 1-2 years to complete and includes both a written exam and supervised practicum (Peer Support Canada, n.d.-b). To support their certification process, Peer Support Canada has developed several documents outlining a peer support code of conduct, peer support core values, peer supporter competencies (Peer Support Canada, 2016), as well as standards and principles of practice for peer support workers (PSACC, 2016).

I remember being particularly concerned when Peer Support Canada joined CMHA National, and the certification of peer support was placed under the supervision of a mainstream mental health organization – the very type of service that peer support emerged to resist.<sup>23</sup> In 2021, PSC and CMHA National decided to "redraw their partnership... [and] to re-establish Peer Support Canada as an independent peer-driven organization with its own autonomy, governance structure and staffing" (Peer Support Canada, n.d.-a, para. 5, 2022). However, it remains to be seen what this new partnership will look like in practice.

In *Guidelines for the Practice and Training of Peer Support*, Kim Sunderland et al. (2013) conceptualize peer support on a continuum ranging from "friendship" to "clinical care" (p. 16); however, this document only provides guidance for peer support on the "clinical care" side of the continuum, and only discusses informal peer support in

<sup>&</sup>lt;sup>23</sup> I acknolwedge that other peer support workers share some of my concerns (Alise de Bie, 2022, personal communication). However, since I did not discover any reference to these specific concerns in my literature review, here I have chosen to focus on my own experience of this situation.

passing. Shinjini Bakshi (2021) notes that informal peer supports allow people of colour and Black, Indigenous, and trans communities at increased risk of police brutality to access support without risk of carceral crisis response, and may be better suited to support people who are distrustful of or alienated from traditional services.

Both *Making the Case for Peer Support* and the *Guidelines for the Practice and Training of Peer Support* are commonly referenced and actively shape both perspectives and practices of peer support in Canada. I first came across the MHCC *Guidelines* while volunteering at the Mental Health Rights Coalition (MHRC), a consumer/survivor initiative in Hamilton. Although the MHCC *Guidelines* only provide guidance on the "clinical care" side of the continuum, I understand MHRC to be more closely aligned with what the *Guidelines* refer to as "friendship," due to the naturally occurring style of peer support I encountered there – an informal form of peer support which is not covered by the MHCC *Guidelines*.

Drawing on the definition of professionalization raised by Helena Roennfeldt and Louise Byrne (2021), the MHCC and Peer Support Canada have contributed to the professionalization and governance of peer support work by establishing both required qualifications (through the development of MHCC *Guidelines* and Peer Support Canada certification requirements) and regulatory associations (through the creation of Peer Support Canada). They have also legitimized the field, through Peer Support Canada's certification program and the MHCC's understanding of peer support as "an essential element in recovery-oriented service" (Geertje Boschma & Courtney Devane, 2019, p. 91), preventing peer support workers from "being perceived as unqualified" (Helena Roennfeldt & Louise Byrne, 2021, p. 1446).

The MHCC and Peer Support Canada have contributed to the institutionalization of peer support work through their goals of integrating peer support within the mainstream mental health system and their primary focus on these forms of peer support. This emphasis on formal peer support leaves little attention on the values and practices of informal peer support, and risks presenting clinical peer supports as the only form which peer support can take. Foundational documents on formalized peer support practice represent a discourse dominated by clinical and institutional contexts, enabling further institutionalization.

There is a particular irony inherent in the institutionalization of peer support, which emerged following deinstitutionalization in response to institutional harm and as an alternative to institutional "care." Now, peer support finds itself becoming (re)institutionalized within the very systems it was developed to resist, and peer support workers find themselves forced to adopt the approaches of the institutions they work for.

# LOOKING FOR TROUBLE: CONCERNS & IMPACTS OF PEER PROFESSIONALIZATION AND INSTITUTIONALIZATION

The professionalization of lived experience roles is controversial. Professionalization has been supported as a method to increase role status, funding, the ability to create system change from the inside, support role clarity, and prevent lived experience workers being viewed as a cheap form of labour (Helena Roennfeldt & Louise Byrne, 2021). However, professionalization may also restrict political action and exclude workers from the profession due to educational barriers (Helena Roennfeldt & Louise Byrne, 2021).

As the consumer/survivor movement began accepting government funding, it became less independent, raising concerns of co-option (Wallis Adams, 2020). Receiving funding risks promoting consumer perspectives over more radical voices (Judi Chamberlin, 1990), and has resulted in an increased emphasis on accountability and meeting government goals in peer support practice (Wallis Adams, 2020). Likewise, the professionalization of lived experience roles more generally has raised concerns about cooption and a loss of authenticity, as workers are increasingly influenced by the medical model (Helena Roennfeldt & Louise Byrne, 2021).

In practice, Jijian Voronka (2019) notes that peer workers experience "paradoxical demands for authenticity" (p. 3); by becoming peer *workers*, we become increasingly distinct (as employees and healthcare providers) from the peers and service users we aim to represent, undermining the definition of "peer" as "being of equal standing with another" (p. 6). Peer workers are required to "pass as normal [or professional] enough to work in workplaces and as disabled [peer] enough to authorize our authority" (p. 10), through mediating our behaviour and appearance to fit the current setting and circumstance. Setting up something of an opposition between "peer" and "professional" identity, Jijian Voronka (2019) draws attention to the tension between these discourses; passing as "authentically peer" may place our employment at risk, whereas passing as "professional" may result in our authority being called into question.

Is it possible to be professional in a way that remains grounded within peer values and approaches, or do these discourses inherently contradict one another? Some of the expectations associated with professionalism compromise peer values and approaches – but do things need to be this way?? Drawing on the research of Marjaana Jones and Ilkka Pietilä (2020), Wallis Adams (2020) notes that peer support workers "are redefining professionalism to increase mutuality and make client/provider roles less rigid" – however, these peer support workers still adopted traits of professionals in order to gain

legitimacy within the system (Marjaana Jones & Ilkka Pietilä, 2020). Redefining professionalism may still involve a compromise.

# Part 1: Mutuality...?: Recreating Power Imbalances

The professionalization of peer support brings the potential for increased power imbalances between peer workers and those they support (Helena Roennfeldt & Louise Byrne, 2021), and risks compromising the peer value of mutuality. An emphasis on "professional boundaries" has the potential to compromise peer relationships by increasing power imbalances and recreating a service provider/user binary (Wallis Adams, 2020) – the very service paradigm which peer support emerged to oppose. Likewise, Jean Campbell (2005) notes that "formalizing social support through professional mental health programs ... strips relationships of intimacy, closeness, affection, and sexual contact ... by maintaining boundaries between people" (p. 23), preventing access to organic peer community (in all its potential messiness!).

The institutionalization of peer support in Pennsylvania resulted in an increased emphasis on completing documentation, which is required for government Medicaid health insurance reimbursement (Wallis Adams, 2020). Writing from Aotearoa (New Zealand), Anne Scott and Carolyn Doughty (2012b) note a similar emphasis on documentation, discussing the tensions between the emancipatory philosophy of peer support and the medical model under which documentation is required. As a technology of surveillance and social control, documentation maintains power relations by making information about peers available to professionals, but not to the peers themselves (Anne Scott & Carolyn Doughty, 2012b).

Judi Chamberlin (1978/2012c) notes that alternative services are "[responsible] to the client, and not to relatives, treatment institutions or the government. Information about the client must not be transmitted to any other party without the consent of the client, and such information must be available to the client" (p. 151). Likewise, the Wildflower Alliance (2013) notes that peer workers "have a primary responsibility to support the voice of the individual without having major functions of the system become barriers to that responsibility," and explicitly states that documentation is a violation of the Massachusetts peer support code of ethics (2019). Use of conventional mental health system documentation practices in peer support can compromise mutuality by giving workers the power (and obligation) to name and frame the experiences of their peers, making them complicit in psychiatric functions of surveillance and social control. This raises the question: to whom are peer support workers responsible – their peers, or the institutions for which they work?

# Part 2: "In" But Not "Of" The System: De-emphasizing Experiential Knowledge

When working within mainstream systems, peer supporters are expected to remain "'in' but not 'of' the system" (Western Massachusetts Peer Network, 2014, para/page #) by not using the language, approaches, or frameworks of the system (Wildflower Alliance, 2013). In other words, peers are expected to rely on peer knowledges and approaches, instead of shifting toward those of mainstream clinicians – a phenomenon known as peer drift (Alise de Bie, 20220; World Health Organization, 2019).

However, Wallis Adams (2020) notes that the institutionalization of peer support in Pennsylvania has resulted in a decreased emphasis on experiential expertise; one participant in their qualitative research study with peer workers notes that some

organizations have "confidentiality standards" which restrict what experiences peer supporters can share with their peers. There is also an increased emphasis on formal education; peers must complete a Certified Peer Specialist training which requires a high school diploma or GED. This education requirement risks disproportionately excluding people of colour and other educationally marginalized groups from entering the peer workforce (Wallis Adams, 2020).

## Part 3: "Agents of Change"?: Individualized Empowerment

In the context of professionalization, the role of peer supporters as "agents of change" (Western Massachusetts Peer Network, 2014) appears to be at risk. A common focus on individual empowerment, at the expense of socio-political empowerment and emancipation, renders the peer support literature depoliticized, impacting practice.

For example, in their Institutional Ethnography of an early psychosis intervention clinic in Ontario, Elaine Stasiulis, Barbara Gibson, Fiona Webster, and Katherine Boydell (2022) discovered a disjuncture between the clinic's goals of providing recovery-oriented care and the experiences of service users. Despite their intention of prioritizing selfdetermination, choice, and empowerment, the clinic engaged in informal coercion practices which were shaped by discourses of medication adherence as a requirement of recovery. Youth were required to meet with medical staff, but were only able to meet with members of the psychosocial/recovery team (including peer support workers) through the referral of medical staff; they were not allowed to meet only with members of the recovery team. Likewise, youth were provided with a choice of which medication to take – but were not able to choose not to take medication at all. Although the clinic

claimed to prioritize youth's empowerment and autonomy, the choices they were given were restricted to those which aligned with the opinions of the medical model.

Robert Emerick (1996) notes that the majority of research on self-help is oriented towards an individualistic discourse of empowerment, excluding an attention to sociopolitical empowerment (emancipation). He notes that most studies are conducted by psychologically-oriented scholars – representing a discipline which is oriented toward individual rather than social explanations and responses. Nearly three decades later, the literature of peer support still seems to reflect this individualistic framework of empowerment. In fact, Wallis Adams (2020) notes that "discourse shifted from empowerment to be independent from the system to 'consumer choice'" (p. 2) following a "reformist turn" toward accepting government funding and working alongside less radical groups.

Through individualizing discourses of empowerment, peer supporters are oriented toward individual rather than socio-political change. Our ability to advocate for sociopolitical and systems change may also be further undermined by restrictions relating to the context of our employment.

# **CHAPTER 4: EXPLORING INSTITUTIONAL ETHNOGRAPHY**

Now that I was preparing to begin my research, I had to decide on a theoretical frame to guide my work. I had already decided that I wanted to use peer support as a research method/ology, and have my research be informed by a triangle model of peer work.<sup>24</sup> However, I needed a theoretical frame to guide my work. Through the gentle guidance of my professor Allyson Ion and thesis supervisor Alise de Bie, I found my way to Institutional Ethnography.

### **INTRODUCING INSTITUTIONAL ETHNOGRAPHY**

During my research methods class, my professor Allyson Ion introduced me to the framework of Institutional Ethnography, which she had used for some of her research. Institutional Ethnography is a critical social theory/methodology (Grainne Kearney et al., 2019) or "method of inquiry" (J. L. Deveau, 2009, p. 1) developed in the 1960s by Canadian sociologist Dorothy Smith (Stella Ng, Laura Bisaillon, & Fiona Webster , 2017), which focuses on revealing how people's everyday lives are shaped by institutional forces ("ruling relations"; Grainne Kearney et al., 2019). Institutional Ethnography neither "start[s] [n]or end[s] in theory" (Grainne Kearney et al., 2019, p. 19; Janet Rankin, 2017b); rather, it begins with participants' descriptions of their everyday work, using their experiences as both the starting point and method of inquiry.

I was intrigued by this approach, which I had not heard about before. I made a mental note: "*Look into this more. I don't think it will work for this research project, but maybe something to explore for the future?*" Initially, I didn't think that Institutional Ethnography would fit my research project. I wanted to use theory to explore the

<sup>&</sup>lt;sup>24</sup> Described in <u>Chapter 1 – Uncovering a Triangle Model of Peer Work</u>.

professionalization of peer support, and Institutional Ethnography doesn't use theory in traditional ways.

Over the years, I had come to realize how much I love theory – one reason being the ways that theories have changed my perspectives, and consequently, my entire life. Through learning about critical disability studies and Mad studies through my involvement in Mad community, I experienced a paradigm shift; I discovered an entirely different way of thinking about my experiences in the world, which allowed me to turn away from bio-psychiatric indoctrination.<sup>25</sup> I thought that theories from critical disability studies and Mad studies had a lot to offer, and I wanted to draw on them for my research.

Still struggling with deciding on a theory, I sent some of my thoughts to my thesis supervisor, Alise de Bie. They mentioned that some of my writing sounded aligned with Institutional Ethnography; suddenly, something clicked. Their explanation of how Institutional Ethnography could apply to the field of peer support suddenly made it feel possible. I read a little more, and realized that my earlier paper and webinar on peer support documentation practices<sup>26</sup> was already aligned with key principles of Institutional Ethnography. I started with my own "felt trouble" of everyday documentation work and analyzed (textual) guidelines for peer support documentation – tracing some of these suggestions back to a research paper. I started to feel like an Institutional Ethnography on peer support was possible, after all – in fact, I had already done one!

<sup>&</sup>lt;sup>25</sup> Described in Chapter 1 – The Hamilton Mad Students' Collective.

<sup>&</sup>lt;sup>26</sup> Described in <u>Chapter 1 – An Entry Point to Institutionalized Peer Support</u>.

# Getting Lost in Institutional Ethnography: Confusion & Finding a Paradigm Shift

Although I had made the decision to use Institutional Ethnography, I still found myself feeling very confused by this new (to me) "method of inquiry." I felt like I understood the premise, but often found myself getting lost in the technical terms (which I found very vaguely defined) and unique approach of Institutional Ethnography. Dorothy Smith has described Institutional Ethnography as a "paradigm shift" (2005, as cited in Janet Rankin, 2017b, p. 3) – an entirely different approach to understanding the social world. I think many of my challenges in adopting Institutional Ethnography were a result of this paradigm shift, as I tried to develop this new way of thinking.

In January, I began a new set of courses, and was surprised to discover that one of my courses was all about Institutional Ethnography! I was excited to learn more about this theory, immerse myself in existing research, and practice doing and thinking in Instituional Ethnography for my assignments. During the first class, my professor Laura O'Neill recommended a book written by Marie Campbell and Frances Gregor (2002), called *Mapping Social Relations: A Primer in Doing Institutional Ethnography* (2002), which was developed to be an accessible guide to understanding and doing Institutional Ethnography. I bought a copy and began reading it; I started making my own "paradigm shift," although I still didn't feel completely comfortable with Institutional Ethnography.

In March, Dorothy Smith and Allison Griffith (2022) released their new book, Simply Institutional Ethnography: Creating a Sociology for People. I was excited to read another book that would help me deepen my understanding of Institutional Ethnography. Although I did not find this book nearly as "simple" as the title seemingly suggested, it complimented the book by Marie Campbell and Frances Gregor (2002) well and provided additional clarification when *Mapping Social Relations* left me with unanswered questions.

### A HISTORICAL EXPLORATION OF INSTITUTIONAL ETHNOGRAPHY

Through these books and my course readings, I learned about the history of Institutional Ethnography, and how this history shaped it into the theory it is today. Institutional Ethnography emerged from Dorothy Smith's critique of mainstream sociology, and its inability to "start in the real world" (Grainne Kearney et al., 2019, p. 18), along with her own felt disjuncture between her everyday lives as an academic and parent. In mainstream approaches, theory abstracts and objectifies what actually happens and the everyday experiences of these happenings, displacing people as knowers and doers (Grainne Kearney et al., 2019; Stella Ng et al., 2017). At the Women's Research Centre in Vancouver, which Dorothy developed to support women's movement activists, she remembers being told: "the problem with you sociologists, is that you always end up studying us" (Dorothy Smith & Allison Griffith, 2022, p. 3).

Whereas mainstream sociology positioned women [people] as *objects* of study, Dorothy hoped to create a method of inquiry through which they would be *subjects* of study instead. As such, Institutional Ethnography is positioned as an *alternative* sociology – a sociology *for* (rather than *about*) people (Marjorie DeVault & Liza McCoy, 2012). Institutional Ethnography resists the theorization of experience, instead focusing on what actually happens and how it is coordinated by external (extra-local) forces (Stella Ng et al., 2017; Debra Talbot, 2020).

Institutional Ethnography is commonly referred to as a Marxist-Feminist approach (Grainne Kearney et al., 2019), due to Dorothy's influence from Marxist historical

materialism (J. L. Deveau, 2009; Yang Yann Foo et al., 2021) and feminist consciousness-raising practices (Marie Campbell & Frances Gregor, 2002). George Smith (as cited in Grainne Kearney et al., 2019) notes how Dorothy's ontological shift arose from her readings of Marx, whereas her epistemological shift came from her involvement in the feminist movement. Below, I briefly describe the ontological and epistemological underpinnings of Institutional Ethnography.

#### Marxist Historical Materialism: Outlining a Social Ontology

Ontologically, Institutional Ethnography draws on the historical materialist perspective of Karl Marx, through focusing on what actually happens in peoples' lives (J. L. Deveau, 2009). Materiality is present both through informants' descriptions of their everyday work ("what actually happens") and the texts that govern this work (Janet Rankin, 2017b). As a materialist inquiry, Institutional Ethnography is focused on concrete descriptions of what (and how) things happen, as opposed to theoretical abstractions or opinions about these happenings (Stella Ng et al., 2017).

Institutional Ethnography rests on the assumption that contemporary societies are socially organized (Stella Ng et al., 2017) and ruled (Marjorie DeVault & Liza McCoy, 2012) through texts: "documents... in spoken, written, or graphic forms" (Yang Yann Foo et al., 2021, p. 508) "that exist in a materially replicable form" (Dorothy Smith, 2001, as cited in Grainne Kearney et al., 2019, p. 19) and operate as "mechanisms for coordinating activity across [settings]" (Marjorie DeVault, 2006, p. 294). As such, Institutional Ethnography relies on a social ontology that "rejects abstract theoretical explanations" (Grainne Kearney et al., 2019, p. 19) and instead understands social life as being "organized to happen as it does" (Marie Campbell & Frances Gregor, 2002, p. 27) by social relations ("connections among work processes"; Marjorie DeVault, 2006, p. 294) which coordinate activity across time and space (Marie Campbell & Frances Gregor, 2002).

Janet Rankin (2017b) notes that "we are all *organized* [sic] to participate in ruling relations; in the developed world, there is no one who is immune from their power" (p. 2), even outside the context of formal labour relations. Due to the pervasiveness of ruling relations within our everyday lives, Institutional Ethnography defines work "generously" (Dorothy Smith, 1987, as cited in Marjorie DeVault & Liza McCoy, 2012, p. 385) and includes unpaid and invisible work within this definition (Marjorie DeVault, 2006) – in line with feminist (re)conceptualizations of "work."

## Feminist Consciousness-Raising: Embracing a Social Epistemology

Epistemologically, Institutional Ethnography is informed by Dorothy's involvement in the feminist movement, and particularly by feminist processes of consciousness-raising (Grainne Kearney et al., 2019). Institutional Ethnography rests on the assumption that "people are experts in how they live their own lives" (J. L. Deveau, 2009, p. 3) and can provide detailed accounts of both what they do as a part of their everyday work and why (Stella Ng et al., 2017); as such, informants are encouraged to "speak from themselves and their experience" (Dorothy Smith, 1987, as cited in Grainne Kearney et al., 2019, p. 18). In practice, this positions experiential knowledge as both the starting point and method of inquiry.

Marie Campbell and Frances Gregor (2002) note that "all knowing is grounded somewhere" (p. 13); all knowledge is situated within a particular standpoint. Institutional Ethnography rests on the epistemic assumption that "all knowledge is socially

organized... knowledge is never 'neutral'... [but rather] carries particular interests that are embedded in its construction" (Janet Rankin, 2017a, p. 2); "objectivity" is understood as unacknowledged ideological subjectivity. As a result, Institutional Ethnography neither "start[s] [n]or end[s] in theory" (Grainne Kearney et al., 2019, p. 19; Janet Rankin, 2017b); embracing a social epistemology, researchers "do not cede authority to ideas established in the literature... [rather,] they rely on people's experience as the point of entry into inquiry" (J. L. Deveau, 2009, p. 1) and embrace "a way of knowing that is experiential, from the inside" (Grainne Kearney et al., 2019, p. 20).

Using sociological theory in traditional ways can result in the 14<sup>th</sup> floor effect, "whereby theoretical concepts stand in for the social relations that exemplify the theory" (Grainne Kearney et al., 2019, p. 19), embedding institutional interests and displacing people and the local settings in which they work. Instead, Institutional Ethnography draws on participants' situated knowledge/s and experiences of disjuncture to construct a research problematic around which the inquiry is organized and directed (Marie Campbell & Frances Gregor, 2002; J. L. Deveau, 2009; Janet Rankin, 2017b). Disjuncture refers to a tension or disconnect between how something is known from an experiential (local) standpoint and from a ruling (extra-local) standpoint; as Marie Campbell and Frances Gregor (2002) note, "the issue of disjuncture is between different versions of reality" (p. 48).

Institutional Ethnography uses "experience as a method of discovering the social from the standpoint of women's [peoples'] experience" (Dorothy Smith, 1997, p. 392). As such, researchers are required to adopt a "standpoint" and commit to "knowing on behalf of those whose lives [they study]" (Marie Campbell & Frances Gregor, 2002, p. 48). In order words, institutional ethnographers are committed to "taking sides" (Marie

Campbell & Frances Gregor, 2002; Caroline Cupit, Janet Rankin, & Natalie Armstrong, 2021) and viewing the world from the participants' vantage point. This experiential knowledge is also used to generate material descriptions of what actually happens in participants' everyday life, allowing the social relations underpinning these activities to be explicated. Institutional ethnography seeks to explore the coordination of participants' experiences "from the inside out" (Adele Mueller, 1995, as cited in Janet Rankin, 2017b, p. 3).

### **RELEVANCE TO RESEARCH TOPIC**

The focus of Institutional Ethnography is on revealing how peoples' everyday lives are coordinated across settings ("socially organized") by institutional forces ("ruling relations; Grainne Kearney et al., 2019). It is concerned with discovering "how things work," "how they are actually put together" (Grainne Kearney et al., 2019, p. 18), and "how things happen the way they do" (J. L. Deveau, 2009, p. 6). In line with these goals, my study seeks to explore how the everyday experiences of peer supporters are socially organized by professional(izing) and institutional(izing) ruling relations, in order to reveal "how things happen the way they do."

As healthcare professions are increasingly textually-mediated by neoliberal and managerial strategies (Grainne Kearney et al., 2019), Institutional Ethnography is a uniquely appropriate method of inquiry for this study. Healthcare systems are highly professionalized and institutionalized (Trish Reay et al., 2016). Both processes involve (textually) regulating the activities of workers (Trish Reay et al., 2016; Helena Roennfeldt & Louise Byrne, 2021). Likewise, the professionalization and institutionalization of peer support itself shapes the everyday work of peer supporters (Wallis Adams, 2020; Helena

Roennfeldt & Louise Byrne, 2021). Due to the professionalization and institutionalization of both peer support and the broader healthcare systems through which institutionalized peer support is embedded, Institutional Ethnography provides a method of inquiry through which these ruling relations can be explicated.

# **CHAPTER 5: UNCOVERING A MAD INSTITUTIONAL ETHNOGRAPHY**

After deciding to use Institutional Ethnography, I found myself feeling lonely and lost. I felt lonely because I hadn't been able to find much research using Institutional Ethnography to examine peer work, or through an explicit Mad studies lens. Although Institutional Ethnography neither starts nor ends in theory, the positionality of researchers inevitably impacts both research procedures and analysis. I wondered: what would a positionality of madness offer Institutional Ethnography in way of its ontological, epistemological, and methodological groundings? I found myself longing for mentorship and guidance on how these frameworks could be blended together.

## ALIGNMENT WITH PSYCHIATRIC CRITIQUE

Throughout my exploration, I came to discover the various alignments between Institutional Ethnography, the psychiatric consumer/survivor movement, and critical mental health / anti-psychiatry perspectives. In particular, Institutional Ethnography has roots in the critique of psychiatry as an institution. In 1975, Dorothy co-edited a book of essays regarding feminist perspectives of psychiatry, including a chapter written by mental patient liberation movement leader Judi Chamberlin (Dorothy Smith & Sara J. David, 1975). Dorothy Smith (1978) has also used Institutional Ethnography to explicate the ruling relations behind the psychiatrization of women (1990). As a more recent example, anti-psychiatrist Bonnie Burstow edited an anthology called *Psychiatry Interrogated* comprised of chapters using Institutional Ethnography (2016). I raise these examples to draw attention to how Dorothy's work has both informed and been informed by psychiatric critique, and the connections between Institutional Ethnography and the psychiatric consumer/survivor movement.

# ALIGNMENT WITH PEER WORK

As I reviewed the theoretical underpinnings of Institutional Ethnography, I was struck with the alignment between this method of inquiry and some of the practices of peer support. In addition to the shared commitment to leveraging experiential knowledge, I noticed connections in relation to the terms of "disjuncture" and "standpoint."

Although the language of "disjuncture" was new to me, I recognized how disjuncture showed up in my life as a peer, through the text of medical documentation. When I reviewed my medical files years ago, I was struck by how disconnected these case files were from my own understanding of my situation. As a peer, I already recognized this disjuncture in my own life. Over the summer of 2022, I took a training on Intentional Peer Support (IPS) created by Shery Mead (2019) and discovered how peer support practice also recognizes disjuncture. For example, one module focused on exploring the differences between conveying our experiences through language of "symptoms" (e.g., low affect) and more descriptive language (e.g., an aching emptiness). Mental health concepts and diagnoses are used to stand in for our actual, embodied, and affective experiences – displacing (and objectifying) them in the process.

The language and frameworks of the mental health system represent ideological narratives, which "transform personal accounts into forms that are intelligible to institutional goals and norms" (Shoshana Pollack, 2010, p. 1270), creating disjunctures between how our experiences are known locally/personally (experientially) and extra-locally by the mental health system (ideologically). In other words, IPS demonstrates a working knowledge of disjuncture by recognizing the impacts of the differences between personal and ideological accounts, and by encouraging peer supporters to focus on

describing their experiences in their own terms as opposed to using the language of the mental health system to represent their experiences (Shery Mead, 2019).

Additionally, I found that my approach to peer support work already drew on the concept of "standpoint." Institutional Ethnography requires researchers to adopt the standpoint of their participants, committing to "knowing on behalf of those whose lives [they study]" (Marie Campbell & Frances Gregor, 2002, p. 48). When I practice peer support, I work to adopt the standpoint of my peers, seeking to understand their experiences from their perspective. To do so, I draw on my own experiential knowledge, positioning myself as a peer. Personally, I feel that peer support, like Institutional Ethnography, requires us to "take sides" (Marie Campbell & Frances Gregor, 2002; Caroline Cupit et al., 2021); I feel obligated to place the interests of my peers above the interests of the system I work within or my own interests.

## BRINGING A "MAD TURN" TO INSTITUTIONAL ETHNOGRAPHY

While acknowledging that Institutional Ethnography neither starts nor ends in theory, I wanted to (cautiously) bring a "Mad Turn" (Phil Smith, 2017, n.p.) to Institutional Ethnography through incorporating Mad (studies) onto/epistemology and method/ology. As Phil Smith (2017, n.p.) notes:

[Mad Studies] offers a Mad Turn: an "in/discipline"

(Ingram, 2008)

a Mad poesis a Mad Turn that offers a way outta the dead-end of academic logical positivizm anti-founded instead

on/in/through/out/about

a Turn towards the irrational

unreasonable surreal

inappropriate

unmanageable

incredible

illegitimate

an anti-methodology that is crazy as a motherfucker.

a weigh to explore the bawdy lustiness of untoward bodyminds

threw the outrageousness of impossible new imaginariums.

As Richard Ingram (2016) notes, Mad studies must strive toward be(com)ing an "in/discipline" (p. 13) by simultaneously demonstrating the method in our madness, while preserving madness within our method. Mad studies must draw on Mad onto/epistemologies and method/ologies and be committed to "bringing up questions of nonsense and introducing nonsense" (p. 15) in order to settle other academic disciplines (Richard Ingram, 2016).

# Triangular(izing) Epistemology

To "introduce nonsense," I (re)turn to the "Triangle Model of Peer Work."<sup>27</sup> I seek to know *through* triangles, embracing a triangular(izing) epistemology which simultaneously attends to the caring, knowing, and change-making functions of peer work. I believe that these elements are interdependent and mutually reinforcing. This

<sup>&</sup>lt;sup>27</sup> Described in <u>Chapter 1 – Uncovering a Triangle Model of Peer Work</u>.

framework comes from my reflections on both my experiences within HMSC and consumer/survivor movement histories.

Through sharing our stories with one another, peers are able to support one another, develop and share individual and community/co-produced knowledges, and mobilize this knowledge to advocate for social change and self-help alternatives (Alison Faulkner, 2017). Hearing these stories allows us to learn about each other's experiences and provides an opportunity (perhaps responsibility?) to work toward social change.



I do not aim to theorize through the use of this model; rather, these elements are used to "inform my noticing and method of analysis" (Debra Talbot, 2020, p. 693) in order to "shed different lights on people's problems" (Janet Rankin, 2017b, p. 8), intentionally drawing my attention to the care, knowledge, and change functions of peer

# Figure 2: Triangular(izing) Epistemology

support practice. This framework served as an overarching framework for the study itself: leveraging (caring) peer support groups both as a site of knowledge co-production and the foundation for social change. It also guided my initial discussion questions for participants, by dedicating time to talk about each component.

### Peer Support as Method/ology

In taking a "Mad turn" on Institutional Ethnography, I draw on long-honoured traditions of peer support as a method/ology for knowledge generation in Mad communities. As Alison Faulkner (2017) notes: "if experiential knowledge is the bedrock of survivor research, then peer support (and self-help) is, arguably, the bedrock of experiential knowledge" (p. 10). Instead of using traditional approaches to Institutional Ethnography research through interviews and focus groups, I wanted our discussions to take the form and function of peer support groups – using peer support as a method/ology of data generation. My hope was that these peer support groups would allow participants to access informal peer support from their (peer support worker) peers, generate new co-produced knowledge through dialogue, and provide the foundation for change.

I hoped that this would provide a foundation through which participants knew their experiential knowledge was valued and centred throughout the research process, and enable participants to feel more comfortable engaging. Moreover, this framework unsettles dominant research practices of extraction, which often prioritize benefits to academic literature (and researchers) over those of participants. This framework allows participants to *personally* benefit from participating in the study, by providing an opportunity to reflect with and be supported by their (peer support worker) peers – functioning similarly to a community of practice. In short, albeit perhaps more

confusingly, I wanted to use a peer support group for peer support workers to access peer support around experiences of peer support professionalization.

# **CHAPTER 6: DESCRIBING THE EVERYDAY WORK OF RESEARCH**

With my literature review completed and a working understanding of my theoretical framework, I was (almost) ready to begin my research. However, I still needed to figure out how I would put this theory into practice, and how I would (practically) run the study. After completing several steps in preparation for the study, I began meeting with a small group of peer support workers in order to explore their everyday experiences and discover the ways in which they were "hooked into" (Janet Rankin, 2017b, p. 2) a common set of ruling relations.

#### PREPARATION

Prior to beginning the research, I undertook several steps in preparation. First, I developed a preliminary research problematic, grounded within my own experiences and "felt trouble" as a peer support worker engaging in documentation practices. I submitted a proposal for ethics review, and recruited peer support workers to participate in the study. Lastly, I considered how to create a peer support environment within focus groups, so I could use peer support groups as a method/ology instead of traditional research focus groups.

# Uncovering a Problematic

A common starting place within Institutional Ethnography is within "the researcher's reflection on [their] own experience" (Marjorie DeVault & Liza McCoy, 2012, p. 383); it is here where my inquiry begins, within my own experiences and felt "trouble" (p. 384) as a peer support worker. Throughout the past decade, I have noticed a disjuncture between how I know peer support (experientially), as how it is known from an institutional standpoint.

As part of my BSW studies, I have previously written (Calvin Prowse, 2020) and delivered a webinar (Calvin Prowse, 2021a) about my experiences with documentation in peer support practice,<sup>28</sup> outlining a disjuncture between institutional goals of ensuring "quality of care," peer support philosophies of mutuality and self-determination (from a peer support worker standpoint), and impacts of surveillance and social control (from a standpoint of peers accessing service). I have also written (Calvin Prowse, 2022) about the impacts of mandatory suicide reporting in peer support practice, exploring the disjuncture between the stated goals of "care" and the methods of coercion, forced hospitalization, and restraint which may be experienced as anything but caring.

From these experiences and reflection, I identified a preliminary problematic for my study, centred around exploring the impacts of peer support professionalization – a process which textually mediates peer support practice through its standardizing, regulating, and gatekeeping functions (Helena Roennfeldt & Louise Byrne, 2021). Throughout the study, I adjusted my problematic to focus on the effects of peer support institutionalization, as tensions raised by participants appeared to be more reflective of institutional(izing) forces than professional(izing) ones.

#### **Recruitment**

Prior to recruiting participants for the study, I submitted information about the study to the Hamilton Integrated Research Ethics Board (HiREB) for review (Project #14693). Once the study received ethics board approval, I began reaching out to peer support organizations across the province.

<sup>&</sup>lt;sup>28</sup> Described in Chapter 1 – An Entry Point to Institutionalized Peer Support.
I shared information about the study through my professional and collegial (peer support) networks, and asked organizations to share this information with peer support workers they were connected to. This information included a brief description of the study, a letter of information, and a promotional graphic. I contacted a variety of peer support organizations across Ontario and asked them to share information about the study with peer support workers at their organizations, and through any other networks of peer support workers they had access to.

I contacted the Executive Director of the Ontario Peer Development Initiative (OPDI), Laura Pearson, who shared information about my study through the provincial OPDI "NewsToGo" newsletter. I also shared information about the study with four other peer support organizations across the province: one hospital, one consumer/survivor initiative, and two grassroots peer initiatives<sup>29</sup>. These organizations were selected to ensure that peer support workers within a broad range of settings would have the opportunity to participate, and that information of the study would reach workers in various locations across the province.

To ensure this research project was feasible for the short time frame of an MSW thesis, I placed some restrictions on who was eligible to participate. Participants were required to be peer support workers in Ontario, providing peer support around mental health and/or substance use. I limited peer support workers to this scope of practice, out of an awareness that peer support in other sectors (cancer, homelessness, 2SLGBTQIA+,

<sup>&</sup>lt;sup>29</sup> I have chosen not to list all the organizations which were sent information about the study in order to protect the privacy of participants. Because the peer support sector is fairly small, listing the names of these organizations could allow participants to be identified through their relationship to them. I have mentioned sharing information with OPDI because the OPDI newsletter is distributed to a wide range of organizations and individuals across the province, and therefore poses less risk of making participants identifiable.

#### MSW Thesis – Calvin Prowse

etc.) may operate in different contexts, draw on different knowledge sources, and be bound by different sets of ruling relations. In other words, broader forms of peer support may be distinct in both form and function from the type of peer support that arose from the psychiatric consumer/survivor movement. I placed a geographical boundary (Ontario) to ensure that the work of participants would be implicated in a common set of ruling relations, as healthcare legislation in Canada is mandated on the provincial level.

I intentionally adopted a broad definition of "peer support worker" to recruit participants working across a diverse range of contexts within the mental health and substance use sector. In the information letter and promotional advertisements, I noted that peer support workers were invited to participate whether they were working in paid or unpaid (volunteer) roles, within formal or informal contexts, and in a wide variety of workplace settings: clinical, interdisciplinary, hospital, community, grassroots, peer-led settings, or within consumer/survivor initiatives (CSIs).

To express their interest in joining the study, I invited prospective participants to complete a brief online questionnaire hosted through the McMaster University version of LimeSurvey. This survey collected their consent to participate in the study, their contact information and availability, their background in peer support, and their preferences for being credited in the research study. I used the information provided on this survey to determine who would be invited to participate, aiming to reflect a diverse range of backgrounds, employment contexts, and years of experience providing peer support.

I invited the selected peer support workers to participate in a series of four 1-hour focus groups, with one-on-one interviews available as an alternative method of engagement. For their participation in focus groups and/or interviews, I provided each

participant a \$25 gift card of their choice for each session they participated in, up to a total of four sessions (\$100).

Following our final session<sup>30</sup>, I asked participants to complete another survey. This survey collected additional demographic information and provided participants an opportunity to update their preferences for being credited in the study, in case these had changed since the first survey. Participants were also asked if they would like an opportunity to review their biography and quotes being used in the manuscript prior to publication.

## Creating a Peer Support (Group) Environment

To use peer support groups as a method/ology for data generation, I needed to create a peer support environment which differentiated our discussions from more traditional focus group methods. To create these peer support groups, I encouraged participants to use the group as a space for mutual support, provided them with an opportunity to collaboratively create a set of group norms, and took a less active facilitator role.

During our first session, I explained to participants that I hoped they could use our sessions as a peer support group through which they could support each other through their experiences and challenges. As peer support workers, all participants were aware of the framework of peer support. As such, I did not feel the need to describe what a peer support group involves; instead, I allowed them to draw on their own experiential

<sup>&</sup>lt;sup>30</sup> I refer to our conversations as "sessions" or "discussions", regardless of whether they were in the form of focus groups or one-on-one interviews, as the process was similar for both.

knowledge of peer support to determine how to engage with one other throughout our sessions.

During our first focus group, I invited participants to collaboratively create a set of "group norms" to guide our interactions with one another throughout the study. In my experience both engaging in and facilitating peer support groups, these groups often begin by collaboratively creating a set of group norms. These group norms allowed participants to share what they needed from each other in order to comfortably participate in discussion, and provided an opportunity for them to build a sense of comradery and rapport with one another through a collaborative activity.

We created group norms using the "whiteboard" function on Zoom, which allowed participants to independently add their thoughts to a collaborative space. I also invited participants to share their thoughts verbally or through the chat box if they preferred to do so, which I then summarized and added to the whiteboard. After I provided an initial suggestion of "confidentiality" (a requirement of their participation in the study), participants developed the following guidelines:

- Unconditional high regard
- Being non-judgemental
- Validating everybody's perspective, journey, and reality
- Holding space for each other, so that we can take risks, be vulnerable, and share

These group norms helped us ground our discussions in a common set of expectations of one another. However, creating a peer support environment involves more than just calling it peer support and creating group norms – it also requires adopting a different style of engaging with one another: as peers. Instead of adopting an "expert"

role which reinforced researcher/participant hierarchies, I wanted to minimize interactional power dynamics and allow conversation to emerge organically.

During our focus groups, I took a less active facilitator role than what might typically be expected in Institutional Ethnography. To uncover ruling relations, institutional ethnographers need to direct conversation in ways that make this explication possible – by tracing connections among work processes. However, during our group peer support conversations, I aimed to position myself as a peer moreso than a facilitator. Although I provided preliminary discussion questions to initiate conversation and followed up on interesting threads of discussion, I took more of a "hands-off" approach<sup>31</sup> which allowed our conversations to emerge more organically. In doing so, I aimed to prioritize the peer support function of our group over the research function.

Throughout our peer support (focus) group meetings, I worked to adopt the standpoint of my participants, in order to "take sides" and see the world as they do. I engaged with participants as a (peer support worker) peer, and shared some of my own experiences that connected to stories shared by participants. To enable us to develop supportive peer relationships with one another, I structured the research around a series of four focus group discussions, taking place once every two weeks. This allowed both participants and myself time to get to know one another and build rapport, in order to increase our comfort sharing and being vulnerable with one another. Throughout our focus groups, participants regularly supported one another with their experiences, validated each other's perspectives and feelings, and connected their own experiences to those of others.

<sup>&</sup>lt;sup>31</sup> In many of our focus groups, we only had time to touch on one or two of my preliminary discussion questions.

Although this approach did create challenges in acquiring the right type of data to support explication (i.e., discussion of work and texts) through Institutional Ethnography, it was methodologically and ethically important to me that our conversation could emerge naturally and that power dynamics were minimized by allowing participants to direct conversation. Although Institutional Ethnography does follow the lead of participants by centring their "felt trouble" in analysis, it does so with the goal of uncovering work processes; in these groups, I aimed to provide participants with more control over where our discussions led us, even if they were not relevant to the research question.

One-on-one interviews took more of a traditional approach, and I took more of a lead in prompting new discussion topics and asking questions with the goal of uncovering work processes. In one-on-one interviews, power dynamics were heightened, as participants were discussing their experiences directly with me (as a researcher), as opposed to a larger group of (peer support worker) peers. This environment meant that conversation was not possible between participants, and discussion questions were answered much more quickly. Although I also engaged as a peer during these discussions by connecting participants' stories to my own experiences, to me, these interviews felt more like traditional research than peer support. However, because I had more time to speak with a single participant, I used these interviews as an opportunity to dig deeper into responses and develop a deeper understanding of work processes involved in these participants' everyday work.

#### **DATA COLLECTION & ANALYSIS**

With Institutional Ethnography, data collection and analysis are not distinct stages per se; rather, they wrap around one another in an iterative, non-linear process (Janet

Rankin, 2017b). Our discussions followed an iterative process that responded to new developments as they arose, "rather like grabbing a ball of string, finding a thread, and then pulling it out" (Marjorie DeVault & Liza McCoy, 2012, p. 383). Analysis began during our conversations together, as I developed a greater understanding of the disjunctures faced by peer support workers and the connections among work processes which resulted in these felt troubles. Below, I describe how I approached the work of both data collection and analysis.

# Facilitating Discussion

First-level data for the study was collected by "talking with people" (Marjorie DeVault & Liza McCoy, 2012, p. 384) – in this case, peer support workers. Through peer support (focus) groups and interviews, I asked participants about their everyday experiences and (work) lives and learned about various pieces of text involved in governing their work. At the beginning of each session, I reminded participants of our group norms and provided a short summary of our prior session, in order to re-orient participants to our previous discussions.

During our conversations, I asked participants a variety of questions aimed at exploring what these peer support workers do in their everyday work (Elaine Stasiulis et al., 2022), how they know what to do (Caroline Cupit et al., 2021), and how they work with various pieces of text (Marjorie DeVault & Liza McCoy, 2012). The overarching goal in asking these questions was to elicit material descriptions of what participants do as a part of their everyday work, with an attention to how (and through which texts) their activities are coordinated (Marjorie DeVault & Liza McCoy, 2012; Janet Rankin, 2017b). Drawing on a triangular(izing) epistemology,<sup>32</sup> focus group meetings were framed around three overarching topics: (1) care, (2) knowledge, and (3) change, with the fourth and final focus group providing participants an opportunity to share their ideas for change. In addition, I presented a "map" of our conversations to participants at this session, providing an opportunity for them to ask questions, provide feedback, make corrections, and provide additional clarification.

I created four to six preliminary discussion questions for each session and emailed these to participants in advance so that they had an opportunity to review them and think through their responses. Prior to each session, I reviewed and revised planned discussion questions to integrate new questions that emerged for me during our previous sessions. I used these preliminary discussion questions as prompts to initiate discussion, but did not prevent participants from going "off topic" or taking our conversations in new, unplanned directions, and also asked participants other questions as they arose from our discussion.

I provided participants with the option of engaging in one-on-one interviews as an alternative method of engagement for those who were unable to attend one or more of the focus group sessions. Preliminary discussion questions for one-on-one interviews largely mirrored those used in focus groups; however, additional questions were also added in order to reflect topics which emerged during the corresponding focus group. With these participants' permission, a brief summary of our interview was brought back to focus groups in order to inform the group discussion. Over the course of the study, I facilitated a total of four focus group discussions and five one-on-one interviews.<sup>33</sup>

<sup>&</sup>lt;sup>32</sup> Described in <u>Chapter 5 – Triangular(izing) Epistemology</u>.

<sup>&</sup>lt;sup>33</sup> This number does not include the one interview I conducted with a participant who later withdrew from the study.

Throughout our discussions, I "check[ed] my understanding as it develop[ed]" (Eric Mykhalovskiy, 1999, as cited in Marjorie DeVault & Liza McCoy, 2012, p. 385). To do so, I summarized key points and "offer[ed them] up to [participants] for confirmation or correction" (Eric Mykhalovskiy, 1999, as cited in Marjorie DeVault & Liza McCoy, 2012, p. 385), and asked for clarification or more information when I was unsure. Likewise, I presented a map of our discussions to participants during our final focus group, so that they had an opportunity to provide feedback or make corrections. Lastly, I provided an opportunity for participants to review both their biography and quotes being used in the manuscript, to allow for further feedback, revisions, and clarifications. These processes are forms of "member checking" (Yang Yann Foo et al., 2021, p. 511) which I used to ensure the accuracy of my interpretation and the credibility of my results.

#### Interrogating Text and Discourse

Whereas first-level data (experiences shared during interviews and focus groups) aims to gain material descriptions of everyday work, second-level data is concerned with explicating how these experiences are socially organized (Stella Ng et al., 2017). To collect second-level data, I analyzed texts which were implicated in socially organizing peer support workers to work in the ways they do. I ultimately analyzed four main texts: First, I analyzed an extra-local text originating from an institutional standpoint (i.e., healthcare legislation) which, although not explicitly mentioned by participants, was latent in their work within healthcare settings. Second, I drew on broader societal discourses (i.e., discourses of professionalism) referenced by participants. I also explored texts referenced by participants through their descriptions of creating and reading local

texts (i.e., documentation) and feeling devalued by organizational texts (i.e., compensation frameworks); however, I did not access these texts directly or explore them beyond participants' descriptions of them.

During our discussions, I asked participants how they used these texts, as well as how the texts were used by others: what someone does with or because of the text, how the text comes to them, and what they need to know in order to use the text (Marjorie DeVault & Liza McCoy, 2012). Through analyzing these texts and how they were used, I was able to begin explicating how the everyday work of peer supporters is hooked into the ruling relations these texts constitute and re-present.

Not all texts used for explication were explicitly mentioned by participants as involved in shaping their everyday experiences. However, these texts did connect to disjunctures experienced by participants, and, as such, were implicated in shaping their experiences. While some of these texts were actively implicated in shaping the experiences of peer support workers (e.g., legislation), others were chosen to reflect broader discourses at work behind these experiences (e.g., discourses of professionalism).

#### Analytical Tools

I engaged in the analytic strategies of "writing accounts" and "mapping" (Janet Rankin, 2017b) to support my analysis, refine the research problematic, and empirically explicate how the experiences of participants were socially organized. Both of these strategies are indexical; they allowed me to organize data by the links and relationships between them, and "point to ... something going on in the place where it occurs" (Janet Rankin, 2017b, p. 6). Throughout the process, I aimed to maintain dual focus of "keeping the institution in view" (McCoy, as cited in Grainne Kearney et al., 2019, p. 19) and

"keep[ing] the people in view" (Timothy Diamond, as cited in Janet Rankin, 2017b, p. 5). In other words, I aimed to maintain an analytic view on the institution, while ensuring that my analysis remained grounded in its actual impacts on the everyday lives of participants.

I wrote accounts by supplementing participant accounts of their everyday work with descriptions of the processes, texts, and work of others not included within their account, to reveal relationships between local and extra-local work (Janet Rankin, 2017b). This strategy allowed me to clarify what analytical "thread" I was following and prevent me from becoming overwhelmed with the large amount of data I had collected. The strategy also allowed me to organize my data (and thoughts) to reveal the connections between everyday work and texts. By writing accounts, I was able to uncover areas of disjuncture and determine what pieces of data were relevant to explicating the ruling relations behind these felt troubles.

After writing these accounts, I mapped them by tracing the relationships of work and text from local experiences to institutional processes (Nicole Dalmer, 2021), in order to visually demonstrate how local activities were textually-mediated via ruling relations (Janet Rankin, 2017b). Throughout the research process, I revised these maps several times as my analysis developed.

My initial map aimed to capture all relevant research data and the connections between them. However, this map included several different analytical threads, not all of which have been followed; if Institutional Ethnography is "like grabbing a ball of string, finding a thread, and then pulling it out" (Marjorie DeVault & Liza McCoy, 2012, p. 383), this map represented a tangled ball of yarn, the threads of which had not yet been pulled out or untangled. Moreso than an Institutional Ethnography map, this map operated as a summary of our conversations together. During our last focus group, I presented this map to participants for feedback and review, so that I could check my understanding of our conversations and seek clarification when needed.

Following this presentation, I created separate maps for each analytical thread being followed, which included only data relevant to each particular thread. I continued to revise these maps as I wrote about my findings, in order to prevent me from drifting away from the main analytical threads. I added key points of analysis, discussion, disjuncture, work, and text to these maps throughout the writing process, in order to draw my focus to the connections between them. A copy of these maps can be found in <u>Appendix A</u>.

#### **Reflection & Review**

Throughout the research process, I engaged in regular reflection on my conversations with participants. During each session, I took brief notes of key points of discussion so that I could return to certain topics if I felt they could benefit from additional explanation or exploration. Following each session, I recorded an audio reflection on the key points of our discussion, as well as my preliminary thoughts on how participants' contributions were connected. A week after each focus group, I met with my thesis supervisor Alise de Bie to share and discuss key points from the peer support group discussions and my preliminary thinking. I created short PowerPoint presentations of key topics and quotes to structure these conversations, the creation of which provided another opportunity for me to reflect and organize my thoughts.

I also transcribed several of the peer support group conversations; however, due to time constraints, not all sessions could be fully transcribed. Three focus groups and one interview were fully transcribed, while one focus group and four interviews were not.

Although our sessions were automatically transcribed by Zoom, these transcripts needed to be corrected and formatted to be easily used for analysis. In order to do so, I reviewed these automatic transcripts, made corrections, inserted punctuation, and formatted quotes beside a timestamp and indicator of the speaker. For some of these transcripts, I also made brief notes about key points to make it easier to sift through data at a later stage. By reviewing audio-recordings and creating transcriptions of our sessions, I was able to reflect further on our conversations and note key points that I had not noticed during the session itself. For sessions that were not fully transcribed, I reviewed the audio recordings so that they would not be inadvertently omitted from analysis, transcribing only quotes that would be used in the final manuscript.

For transcribed sessions, I created a separate document organizing key quotes by topic; for example, all quotes relating to documentation work were grouped together. These groupings were not intended to support thematic analysis; rather, they were created to make it easier to re-locate data relevant to each analytical thread. Alongside key points of discussion, I included an indicator of who was speaking, the session in which it took place, and a timestamp.

#### NEXT STEPS: WORKING TOWARD CHANGE

As an emancipatory "approach for scholarship and activism" (Janet Rankin, 2017a, p. 2), Institutional Ethnography is accountable to those at the standpoint position (J. L. Deveau, 2009) and holds a "dual emphasis on analysis and change" (Marjorie DeVault & Liza McCoy, 2012, p. 387). Unlike other research approaches, the analytic goal of Institutional Ethnography is not theory building, but explication (Marjorie DeVault, 2006); it aims to "generate potentially useful knowledge for *people whose* 

everyday activities are being organized against their own interests [sic]" (Janet Rankin, 2017a, p. 1, emphasis in original).

I needed to ensure that my research was "accountable to those at the standpoint position"; my results needed to be *for* (rather than *about*) the peer support workers in my study. During our third session, I asked participants which topics they felt were the most important to focus on. During this discussion, participants highlighted the importance of focusing on areas related to lived experience, education, professional development, and peer drift. This allowed me to ensure that my research was focused on areas that peer support workers thought were most important, and therefore generating knowledge that would be potentially useful for them. In addition, I created a short summary of the study (<u>Appendix B</u>) geared towards an audience of peer support workers and organizations, so that findings could be more accessible and useful to those implicated within processes of peer support institutionalization

To work toward the goal of change, our fourth session provided participants an opportunity to share ideas for changes that could redress some of the troubles they face in their everyday work. In addition, participants were given the opportunity to continue to meet following the formal conclusion of the research to explore how we could use our analysis to work toward change in peer support institutionalization.

### **INTRODUCING THE PEER SUPPORT WORKERS**

Seven peer support workers completed the preliminary questionnaire, and six were invited to participate in the study. Participants were selected to ensure that a range of peer support contexts (e.g., hospitals, community organizations, and peer-run programs/organizations) and years of experience with peer support were represented. One

participant was excluded from the study in order to ensure focus groups were small

enough to facilitate intimate conversation, and because their employment context was

comparable to that of another participant. One participant withdrew from the study

following the first session; as such, their contributions have not been included in analysis.

The following five peer support workers participated in this study:

**Angela Jaspan** has been practicing peer support for the past five years. She works in a hospital as a part of an interdisciplinary team, alongside a team of peer supporters.

**Hannah**<sup>34</sup> has been working as a peer supporter for the past six years. She currently works in a peer-run program within a larger social service organization which is adjacent to the healthcare sector.

**Jodie** has been practicing peer support for the past two years. She started working as a peer supporter at a grassroots Christian organization, and later moved to working for a non-profit community organization.

**Tracey L. Addison** has been a peer support worker for the past five years. She works in a community-based program for youth with mental health and/or addiction concerns, managed by a hospital. She works on an interdisciplinary team, as the only peer support worker in the program. In addition to her own lived experiences with mental health, she brings along her experiences supporting family members with mental health concerns as well.

**Tyrone Gamble** has been practicing peer support for over twenty years, and currently works as a peer supporter for two separate organizations. He works in the community through a mainstream mental health organization, as well as for a consumer/survivor initiative (CSI) where he supports peers in a local hospital. He is passionate about supporting others with their experiences of hearing voices and parallel realities, as well as Indigenous peer support.

These peer support workers work in several geographical locations across Ontario:

Durham region, the Greater Toronto Area (GTA), Halton, Hamilton, and Ottawa.<sup>35</sup> They

<sup>&</sup>lt;sup>34</sup> This participant chose to be credited by an alias; as such, her contributions are credited to the name "Hannah."

<sup>&</sup>lt;sup>35</sup> Because the peer support field is relatively small, it may be possible to identify participants by the city in which they practice. To protect participants' confidentiality, geographical locations are listed as an aggregate instead of being linked to individual peer support workers.

also represent a range of experience as peer support workers, ranging from two years to over twenty.

In addition, these peer support workers represent a variety of employment contexts. Both Angela and Tyrone work in hospital settings – although Tyrone does this work as an employee of a CSI. Tyrone also works in the community for a mainstream mental health organization. Tracey is an employee of a hospital, but works outside of the hospital in a community-based agency. Hannah works for a peer-run program of a larger social service organization, whereas Jodie works for a non-profit community organization. In short, this study includes the experiences of peer support workers working for hospitals (2; one within a hospital and one within a community-based program managed by a hospital), community organizations (2), peer-run programs within larger organizations (1), and a consumer/survivor initiative (1; although this work takes place within a hospital setting).

The participants also brought different educational histories: three participants have one or more post-secondary education degrees and/or diplomas, and two participants did not complete high school – one of which later received maturity credits to receive their high school diploma, and has since taken several post-secondary courses.

The majority of participants (4) in the study identify as white/Caucasian, and one participant identified as Indigenous.

# **CHAPTER 7: TROUBLING DOCUMENTATION WORK**

This chapter focuses on the work of peer supporters in relation to documentation. Below, I explore the troubles that peer supporters face in relation to documentation, and "trouble" (critique) the ruling relations underlying documentation practices as a whole.

Throughout our discussions, peer support workers in this study mentioned adopting unique approaches to documentation practices: the work of reading notes, writing notes, and sharing information about their peers with colleagues. These approaches generated tensions between peer support workers and their clinical colleagues, who pressured peer workers to adopt (clinical) organizational norms of reviewing documentation and sharing information freely within the peer's circle of care.

### "I DON'T READ MY PEERS' CHARTS": REFUSING INSTITUTIONAL ACCOUNTS

One peer support worker noted how his organization had instructed peer support workers to review notes written about their peers, and how he navigated the tensions that arose for him:

Tyrone: I don't read my peers' charts. I don't need to know that. [...] They tried to have us, years ago, read people's files, and it was like [...] I want the person to be able to [...] be in a relationship with me on their own terms rather than me [...] bringing biases. [...] They're going to share what they want to share with me, and they're not going to share what they don't [want to share].

Tyrone responded to expectations to read documentation about his peers by refusing to comply. Tyrone raised how institutional accounts distort perceptions; as a local text, case files orient healthcare providers toward a particular view of service users, creating "bias" and activating workers to interact with clients in specific ways. Instead of using the institutional narratives embedded in case files to shape his interactions with peers, Tyrone drew on experiential knowledge he gained through conversation with his peers. This

approach allows peers to direct the peer relationship on their own terms and determine for

themselves what information they want him to know.

While not all peer support workers are expected or required to review clinicians' notes about their peers, even if they have access to them, some still engaged in similar strategies of intentionally not reading a peer's file:

Angela: We do get to see, you know, clinicians' notes as well, as a part of our system. [...] When we go to meet somebody up here, [...] they'll ask me if I've read their notes and I say "No, everything that [...] I come up with or think is based on that first interaction, it's – I'm not coming there prepared, having read your file. And, you know, coming at you like I [...] view you as the person who wrote the file [does]." [...] When I come across a new person, I don't know anything. Everything I know from them is what I learned from that first conversation on.

Instead of reviewing case files, Angela engaged in similar strategies as Tyrone – by developing an understanding of her peers solely through conversation and what her peers choose to share. In doing so, she ensured that she does not view her peers as their case files present them, centreing the personal account over the institutional account embedded within documentation. The fact that Angela's peers expect her to have read their files draws attention to how this process is normalized and expected within healthcare settings; peer support workers' refusal to read notes is experienced as an exception to institutional norms.

### "I JUST WRITE THINGS AS REMINDERS": APPROACHES TO WRITING DOCUMENTATION

Some of these peer support workers are required to document their interactions with peers. However, they approached the work of writing documentation in ways that differ from their clinical counterparts: **Tyrone**: In the community, when I work for [a mainstream mental health agency], I'm supposed to write... notes. I usually work with my peers, to together for the last couple of minutes, work together [to write notes]. So, you know, talk about what is OK for me to write on their chart. And I put the bare minimum, sometimes [...] if they talk about their substance use, you know, and they don't want that shared, that's not my role.

Although Tyrone is required to take notes, he managed the tensions this generates by

providing minimal information and working with his peers to determine what to include.

Similarly, Angela wrote documentation by providing minimal information.

However, instead of using documentation to construct a record of her peer's experiences,

Angela used documentation for a different purpose – as reminders to herself:

Angela: We [peer support workers at the hospital] keep notes, but we... don't write anything substantial. I just write things as reminders – like if someone tells me it's their brother's birthday, so then when I go back and look next time, I can just say, "*How was the birthday party?*", that kind of thing... you know?

These notes helped Angela remember details of her peer's life to discuss during future conversations, but do not contain any information that would be particularly meaningful to other clinicians for purposes of providing care. Instead of using documentation systems to gather health information, she used it as a tool to support and deepen the peer relationship.

Some peer support workers are *not* required to write notes about their interactions with peers. When Tyrone is working for a CSI by supporting peers within the hospital, he is not required to take notes. Although he does record statistical information about his interactions with peers, he does so through an anonymous database used for funding purposes:

**Tyrone:** I don't make any notes. [...] We have a database, where I just put in [the] person's name – they become [anonymized as] a number, a statistic [...] for the funders. But I just talk about how long I've talked to them, it – was it in person, was it phone, blah blah blah, where I met them and, just... acknowledge the contact.

In this situation, Tyrone is not required to disclose the content of his conversation with the peer. Instead, he simply logs how long they talked, where they met, and the method of communication.

# "IT'S UP TO [THE PEER]": CONSENT AND SHARING INFORMATION WITH COLLEAGUES

Peer support workers' strategies of providing the bare minimum of information and allowing their peers to determine what is shared extend to sharing information with their colleagues. When peer support workers think that their peer may be a danger to themself or others, they are activated in an institutional process which requires them to share this information with colleagues.

When a peer is in danger, Tyrone shared (only) this information with the peer's case manager and supported his peer to take the lead in sharing any additional information. However, he noted that case managers often request even more information about the situation:

**Tyrone:** Like I also in the beginning [of a relationship with a peer] also let peers know what the boundaries of confidentiality are, [...] if they're in an acute danger to themselves or others, then I have to report it. But I also let them know, usually [when] that stuff comes out. I try to support them being the ones to drive that. [...] You know, there's been times where [...] someone's shared that they're in acute danger, that they're a danger to themselves and they're going to go do something right now, I will connect with their case manager and let them know, so that both of us can support the person – but then the case manager at times [says], "Well, can you give me all the information on what's going on?" It's like, "I'm sorry, I'm coming to let you know... the person's a

danger to themselves, but it's up to them if they want to share that, and what that means."

Tyrone informs his peers about these limits of confidentiality at the beginning of the relationship, which allows them to make an informed decision about what they feel comfortable sharing with him. When a peer was a danger to themselves, he shared this with their case manager. However, he shared only the bare minimum of information – that his peer is in danger – and allowed the peer to direct what additional information is shared.

His decision to approach sharing information in this way was guided by a desire to protect the peer relationship and provide his peers with some control over the situation:

**Tyrone**: And just, you know, again, allowing them to feel that that it's up to them, and that they have some say in – and some control. You know, [not making them] feel hopeless and helpless again. You know? To me it's, that—trying to create, and support, and cultivate, and protect that relationship, for me. Anything that gets in the way of me having that relationship isn't going to be good for me, or the peer.

For Tyrone, sharing only minimal information allows his peers to have some control over the situation, preventing them from feeling "hopeless and helpless" – alluding to peer support values of hope and self-determination. His priority in these situations is to protect the peer relationship and the trust of his peers, which could be compromised by sharing information without their consent. He stressed the priority of the peer relationship, noting that "anything that gets in the way of [the peer] relationship isn't going to be good for me, or the peer."

### "WE'RE NOT THERE TO RAT SOMEONE OUT": OUTLINING PEER CONFIDENTIALITY

The troubles that peer support workers face in relation to writing, sharing, and (not) reading information about their peers can be understood in relation to broader

organizational (clinical) norms, reflecting a disjuncture between how confidentiality is known (and practiced) by peer supporters and their clinical counterparts. As Tyrone notes:

**Tyrone**: It's a very different relationship than clinical, especially when it comes to confidentiality. A lot of, you know, our fellow colleagues in mental health, you know, don't understand why confidentiality [and] the way we protect confidentiality is really important, because, you know, we're not there to, you know, rat someone out, y'know, discover their secrets. [...] I don't think peer support would be what it is without peer confidentiality.

Tyrone outlined a framework of "peer confidentiality" as an orientation and practice of confidentiality grounded in the peer relationship, centring the interests of his peers (privacy) over the interests of the institution (collecting health information). He stresses that peer support is not a tool of institutional surveillance intended to "discover [the peer's] secrets" and "rat [them] out" to others – including to clinicians within the same circle of care. However, he noted that his clinical colleagues don't understand the value of peer confidentiality. While other peer support workers did not use the language of "peer confidentiality" per se, they approached the practice of confidentiality in similar ways.

Tyrone's framework of peer confidentiality was also informed by his experiential knowledge of the impact on the peer relationship when confidentiality is not upheld. He recounted times where peers described feeling "tricked" into sharing their experiences with other peer supporters, who then shared this information with the rest of the team:

**Tyrone**: I've had a lot of peers who have come across peer support where, for example, a peer specialist would share their experience and the person felt... tricked into sharing theirs, and then that experience got shared with everyone else on the team, like, and it was like, it was meant for [...] in that relationship, not to be shared throughout [the team]. [...] So I think confidentiality... is something sacred, I think, when it comes to peer support. [...] It creates a foundation of trust, and connection, and that's, I think, a really important reason to protect that so much. Not to get into peer drift where [...] I'm trying to get information out of them so I can share with the team.

In contrast to clinical practices of sharing information freely within the circle of care, Tyrone noted that disclosures within a peer relationship shouldn't be shared outside of that relationship. He said that confidentiality is "sacred;" it creates a foundation of trust and connection which enables peers to share in a healthy way without fear of judgement. In contrast, Tyrone suggested that approaching peer support with the goal of "get[ting] information out of [the peer]" compromises both confidentiality and the peer relationship, resulting in peer drift.

# "ENTITLED TO ASSUME [...] IMPLIED CONSENT": CONSTRUCTING CLINICAL CONFIDENTIALITY

This disjuncture can be explicated through analysis of how discourses of confidentiality are constructed in extra-local texts. I wondered which texts were involved in the construction of "confidentiality" in health institutions and realized how notions of confidentiality related to legislation surrounding health information privacy. I remembered the *Personal Health Information Protection Act* (PHIPA; 2004, c.3, Sched. A) which governs the collection, use, and disclosure of personal health information in Ontario.

The *Personal Health Information Protection Act* (PHIPA; 2004, c. 3, Sched. A) regulates the practices of all healthcare workers in Ontario, including peer supporters working within healthcare environments (although peer support workers are not specifically named in the legislation). Under PHIPA, personal health information about a patient cannot be shared with other parties without their consent. However, so long as a

health institution has fulfilled its obligations in giving notice of the purpose of its collection, use, and disclosure of personal health information, patients are assumed to have provided implied consent for their information to be collected and shared when they access services:

A health information custodian [...] is entitled to assume that it has the individual's implied consent to collect, use or disclose the information for the purposes of providing health care [...] unless the custodian that receives the information is aware that the individual has expressly withheld or withdrawn the consent. (s. 20 (2))

At this point, I remembered Allyson Ion's (2020) study exploring the experiences of women living with HIV accessing perinatal care, and their concerns around disclosing their HIV status to healthcare providers. Allyson's study discusses how PHIPA allows women's HIV status to be shared between healthcare workers or to other people in their personal lives.

Through Allyson's study, I came to discover that PHIPA "was specifically designed so that it would not present a barrier to the disclosure of personal health information among health-care providers" (Ann Cavoukian & Peter Rossos, 2009, p. 8). As such, unless a patient has withdrawn consent, healthcare workers are permitted to share health information within a patient's circle of care so that their colleagues can provide informed care. Writing, reading, and sharing documentation in ways that abide by the rules of PHIPA becomes an organizational norm; as a result, peer support workers are pressured to conform to clinical norms of reading notes about their peers and sharing detailed information about them with colleagues.

Additionally, I discovered that PHIPA (2004, c. 3, Sched. A) allows for – although does not require – a patient's personal health information to be shared without expressed consent when they are thought to be a danger to themselves or others:

A health information custodian may disclose personal health information about an individual if the custodian believes on reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons. (s. 40 (1))

As such, PHIPA may also explain some of the pressures that peer support workers face in relation to disclosing information when their peers are thought to be a risk to themselves or others. Firstly, PHIPA may permit organizational requirements for peer support workers to tell their colleagues when their peers are in danger. It may also explain why Tyrone was asked for additional information after telling a case manager that one of his peers was in danger; the case manager may have believed additional information would support their goal of "eliminating or reducing a significant risk of serious bodily harm" (PHIPA, s. 40 (1)).

#### DISCUSSION

This disjuncture between how notions of confidentiality and consent are known by peer workers and their clinical colleagues results in tensions at the local level, as peer supporters are pressured by their organizations and clinical counterparts to adopt organizational (clinical) norms of reading case notes and sharing information freely within the circle of care. As noted by these peer support workers, succumbing to pressures from clinical colleagues to conform to organizational (clinical) norms creates the risk of peer drift, as peer supporters begin to stray from peer support values and practices.

However, peer supporters resist these pressures by drawing on the alternative framework of "peer confidentiality." Peer confidentiality prioritizes the peer relationship by allowing peers to determine what information is shared with whom. As such, it

prioritizes the interests of peers (to maintain privacy) over those of the insitution (to collect and share health information). Peer support workers note that peer confidentiality allows for their peers to have greater control over their healthcare information, and results in increased levels of trust in the peer relationship. This approach is also driven by peer supporters' experiential knowledge about the negative impacts on the peer relationship when information is shared without their express consent.

By drawing on a framework of "peer confidentiality," peer support workers resist discourses of confidentiality which position clinicians as entitled to intimate information about a peer's life. As such, peer supporters refuse to be a tool of institutional surveillance – noting that their job isn't to "discover [someone's] secrets" or to "rat [them] out." The framework of peer confidentiality is evident in peer supporters' approach to documentation work: namely, their practices of sharing information with colleagues, writing documentation, and (not) reading documentation about their peers.

Peer support workers provided only minimal information about their interactions with peers, allowing their peers to decide what additional information is included in documentation or shared with other members of the care team. By operating through a framework of "peer confidentiality," peer support workers insist on *express* (explicit) consent from their peers to share information with other members of the care team, even though this is not legally required under PHIPA. By requiring express consent to share information, peer support workers ensure that their peers can self-determine what information is shared about them and with whom. As Tyrone notes, information disclosed within the peer support relationship should not be shared outside of it without the peer's consent or direction. These strategies can be read as a form of resistance to the intended use of documentation: to collect and share personal health information. Instead, these peer

support workers centred the peer relationship and placed control back into the hands of their peers.

Angela's approach to providing minimal information in case notes – by using them as reminders to herself – can be read as a subversive act of resistance to dominant documentation practices. Instead of using documentation for its intended purpose, to record health information, she uses documentation as a tool to deepen the peer relationship. By writing reminders about upcoming events in her peers' lives, such as birthday parties, she can remember to ask about them in the future. This allows her to deepen the peer relationship by focusing on components of her peers' lives that are significant personally, but not necessarily medically.

Likewise, peer support workers' refusal to read documentation written about their peers can be read as an act of resistance to the authority of institutional accounts. Shoshana Pollack (2010) describes the difference between primary (personal) and ideological (institutional) narratives: "primary narratives [are] one's own subjective account of events ... ideological narratives transform personal accounts into forms that are intelligible to institutional goals and norms" (p. 1270).

Documentation is one process through which personal accounts are transformed into institutional accounts, reflecting the perspectives of the institution – for example, by framing peers' experiences through the medical model of mental illness. In doing so, these institutional accounts gain authority to define the experiences of patients, subjugating their personal accounts in the process.

Peer support workers noted the negative impacts of institutional accounts and the possibility of them leading to bias. In this context, I understand Tyrone's discussion of "bias" to reference the ways in which documentation shapes the way clients (or peers) are

known – through a medical model, in a single moment of time, and as their stories were understood by other healthcare professionals. The way that peers are known through documentation also has the potential to shape interactions with them; this may lead peer support workers to direct conversation toward concerns noted by other healthcare professionals, as opposed to allowing their peer to lead the conversation.

By refusing to read documentation about their peers, peer support workers resist the authority of the institutional account to define peers' experiences on their behalf. Instead of relying on institutional knowledge, these peer support workers centre the knowledge gained through conversation with their peers, and what they choose to share with them. In doing so, they prioritize the personal account by allowing their peers to share their stories for themselves. As such, their refusal to read documentation can be understood as an extention of peer confidentiality – as their knowledge of their peer is based on what they willingly share within the peer relationship, as opposed to case notes which they have not been given express consent to read.

### **OPPORTUNITIES FOR CHANGE**

Throughout my exploration of peer support workers' approaches to documentation, I came to discover potential gaps in the ruling relations which govern this work. At one of Tyrone's workplaces – working for a CSI, but within a hospital – he is not required to take "notes" per se. Instead, he enters minimal information about his interaction with a peer into a database for funders, which is then anonymized. He includes how long their conversation was, where they met, and whether the conversation took place in person or over the phone. This example provides one potential approach to minimize the tensions peer support workers face in relation to documentation work.

Instead of completing documentation for the purposes of gathering healthcare information, this approach collects only minimal information for funding purposes. Knowing peer support workers' emphasis on providing minimal information, it is perhaps unsurprising that this approach was adopted by a CSI. This framework represents a structure that is grounded with an emphasis on what Tyrone has called peer confidentiality.

Second, I learned that although PHIPA (2004) assumes patients have provided implied consent for their information to be shared between healthcare providers involved in their care, this consent can be "expressly withheld or withdrawn" (s. 20 (2)). It may be helpful for both peer support workers and their peers to know that consent can be withdrawn. This knowledge could help peers maintain their privacy, and peer support workers defend their choices not to share additional information with colleagues – by noting that their peer has withdrawn their implied consent under PHIPA. Individuals can withhold consent for a specific item to be shared (e.g., a diagnosis), their entire health record, or prevent their information being shared with a specific worker or class of workers (e.g., social workers; Information and Privacy Commissioner of Ontario, 2015).

However, patients cannot prevent workers from recording health information "that is required by law or by established standards of professional or institutional practice" (Information and Privacy Commissioner of Ontario, 2015, p. 21), such as when "disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm" (PHIPA, 2004, c. 3, Sched. A, s. 40 (1)).

At the same time, it is important to note that PHIPA (s. 40 (1)) states that healthcare workers "*may* disclose" [emphasis added] information when a patient is thought to be a danger to themselves or others, implying the role of disclosure. Under

PHIPA, peer support workers are *permitted* but not *required* to share this information about risk of harm – however, in some situations disclosure may be required by organizational policy. Additionally, PHIPA only permits this disclosure of a peer's personal health information when it is believed to eliminate or reduce risk of bodily harm or when it is disclosed following other provisions in the legislation (e.g., between workers in a circle of care). If a peer support worker believes the processes for disclosure may result in an *increased* risk of harm, they may be able to use their own discretion and justify not disclosing.

# **CHAPTER 8: DE/VALUING WORK**

One recurring topic within our conversations was the need for clinicians to recognize the value of both lived experience and peer support practice. In this chapter, I explore how organizations determine the value of peer support workers, and how clinicians reinforce organizational hierarchies which position some roles as more important than others. I understand these actions as a form of work which determines how (and whose) work is valued within institutionalized settings. In other words, I am focused on the "valuing work" that determines how peer support work is (de)valued.

Peer supporters in the study felt that their lived experience was not valued as much as the formal education of their clinical counterparts, as evidenced by how they were (under)compensated by organizations and treated disrespectfully by colleagues. These tensions generated troubles for peer support workers, as they felt their work was treated as a cheap alternative to clinical supports. Below, I describe how organizations and clinical workers determined and described the value of staff members' roles, and trace these actions back to societal discourses which construct what it means to be a "professional" – and therefore, a valuable member of the healthcare team.

### "IT DOESN'T REFLECT THE VALUE OF OUR LIVED EXPERIENCE": DETERMINING SALARIES

Prior to hiring staff, organizations typically create a job description for the role. Job descriptions describe the responsibilities of the role and any required qualifications, which are then used to determine the salary offered to the worker. Tracey described how her organization's human resources (HR) department uses compensation guidelines which determine salaries based on the minimum level of education required for the role:

**Tracey**: In a perfect world... I wish that our [peer support] roles could be compensated differently than the [...] hospital's [...] HR

guidelines. [...] Every role within the organization [...] is compensated on the minimum level of education. And so, in [peer support roles] it's a high school graduation diploma. [...] But that doesn't reflect the work we do, and it doesn't reflect the value of our lived experience. So we're not being compensated for that at all. It's not— it's a requirement, but we're not compensated for that.

Although Tracey works in a community-based program of the hospital as opposed to within the hospital itself, the hospital's compensation framework extends to this setting. Within this organization, peer supporters who do have post-secondary education do not receive increased pay, as salaries are based on the *minimum* level of education required for the role.

Although many of these peer supporters felt that their colleagues and organizations valued their role and perspectives, they noted that their compensation does

not reflect their contribution to the team. This generated tensions for peer supporters, as

their work was positioned as less valuable than clinical supports. One peer support worker

spoke about the tensions they feel under the condition of anonymity:

Anonymous: I guess for me, the elephant in the room, that causes conflict, is I get recognition for the role that I play, for the job that I do, for the contribution I make to the team. But then, as you've heard many many, many times, the financial contribution for what I do is nowhere near anyone else on the team. So [...] I'm valued in all of these ways, but not in a way that's important to me.

Although this peer support worker did feel that their work and contribution to the team was recognized by their organization, they noted a discrepancy between their salary and the salaries of other staff members on the team. Throughout the study, many participants described feeling troubled by the low salaries provided to peer support workers, which caused them to feel that they were not valued as much as their clinical counterparts.

Peer support workers can often be hired at a lower expense to an organization due to common practices of offering low salaries, which shapes the ways that organizations approach the work of making hiring decisions. Tyrone felt that the recruitment work of organizations positions peer support as a "cheap alternative" to other supports:

Tyrone: [We] need to fight the notion that we are a cheap alternative to other supports. But I know there's been [...] the move to, instead of getting one case manager or social worker, [organizations] can get two or three peer support workers. [...] We're not being treated as professional and as experts in our area, we're being treated as less than.

Tyrone described how the lower salary requirements of peer support workers led some organizations to hire several peer supporters instead of one clinical worker, making him feel that peer supporters were not being treated as professionals.

By creating peer support roles, these organizations clearly see a benefit to peer support; however, this presumed value is not reflected in the compensation provided to peer support workers. Instead of being hired solely for their contribution to the organization, peer support workers are hired for being affordable. Although these decisions are likely also impacted by budgetary constraints and organizations' desire to increase the amount of support they can provide, the peer supporters I spoke to find these trends troubling and reflective of broader trends of devaluing peer support work.

#### "SO IS CLEANING STAFF": REINFORCING ORGANIZATIONAL HIERARCHIES

In addition to being devalued by low salaries, one participant described being disrespected by clinical colleagues. Angela described a time when a psychiatrist compared peer support workers to cleaning staff, devaluing their contributions to the team:

Angela: There was a psychiatrist, [...] and... when we [peer support workers] said "*OK*, well we're part of [the] circle of care, we are part of the team at [the hospital]," and the psychiatrist said, "well, so is cleaning staff."

By comparing peer support workers to cleaning staff, this psychiatrist reinforced

organizational hierarchies which position the work of psychiatrists as more valuable than

peer support workers.

Several peer support workers expressed disappointment and frustration at these remarks. However, instead of distancing themselves from cleaning staff to demonstrate their own value, they discussed the immense value of cleaning staff:

Angela: Someone said a remark, you know, that the cleaning staff get to know people, and the people get to know them. And sometimes, you know, there's a kind of person you feel you can entrust. And you know, you coming into their room, you seeing them every day, [...] you can create a bond with somebody, you know, in that role, I mean we're all human beings, and that person is pivotal to making them smile that day, and making them feel better that day, you know? And that was discussed, but it was obviously lost on him, the psychiatrist, you know?

In addition to practical components of ensuring clean and safe environments,

Angela noted how cleaning staff can develop rapport and trust with patients through their

human(izing) interactions and regular contact.

By refusing to position themselves as above cleaning staff, peer support workers

resisted organizational hierarchies and the idea that any one role is more valuable than

others. Jodie noted that everybody on the team is needed, and that everyday has a value.

# <u>"Maybe I'm Supposed to Get My SSW Now": Pressures Toward Formal</u> <u>Education</u>

As evidenced by compensation frameworks, healthcare organizations place a high

value on formal education. Within these environments, peer support workers may feel

expectations to pursue post-secondary education as a way to demonstrate their value and legitimize their knowledge.

Prior to becoming a peer support worker, Jodie accessed peer support at a mainstream organization. Learning about peer support and meeting peer support workers encouraged her to pursue becoming a peer support worker herself. However, Jodie noticed that all of the peer supporters at the agency had a formal education, which caused her to feel like she needed more education to become a peer support worker herself.

Jodie also described feeling an expectation to pursue a formal education as a result of broader societal pressures:

Jodie: When I first [...] started doing peer support, [...] I thought, "Well, maybe I'm supposed to get my Social Service Worker [diploma] now." [...] Like I felt like this... expectation put on me. [...] Societally, or, or maybe [...] this is what was ingrained in my mind, you know, all these years.

Although she did return to school, Jodie later realized that she didn't need a formal education to practice peer support – in fact, she was learning how to peer support simply through doing it.

Jodie's story resonated with my own experiences in the field of peer support. As described previously,<sup>36</sup> I noticed that several peer support job descriptions required or recommended education in particular fields, which led me to return to school for social work so that I could gain qualifications and be more likely to find a position in peer support.

<sup>&</sup>lt;sup>36</sup> Re/turn to <u>Chapter 1: Peer Support Training</u> for a more fulsome description of how peer support job descriptions led to my decision to return to school.

# "[SHARING] FROM THE INSIDE": LIVED EXPERIENCE AND/AS EDUCATION

Compensation frameworks based on formal education represent a disjuncture between how notions of "knowledge" and "education" are known locally (by peer support workers) and extra-locally (by organizations). While organizations may have compensation frameworks that only recognize formal education, peer support workers understand lived experience as a form of knowledge and education.

While clinicians gain knowledge through post-secondary education and supervised practice experience, peer support workers develop knowledge through lived experience. Peers develop experiential knowledge through navigating experiences of distress, recovery, and psychiatrization; accessing mental health services; and sharing experiences with their peers. Peer support workers draw on this knowledge gained through lived experience to support their peers. It is worthwhile to note that peer support workers do not have the exact *same* experiences as the peers they support, although at times their experiences may be similar. However, they use their lived experience as an entry point to relate to their peers, through leveraging shared experiences of navigating mental health services or experiencing distress, recovery, and psychiatrization.

Jodie recounted talking to a peer about addictions, highlighting how her lived experience allows her to relate to her peers. Although clinicians might develop an understanding of addiction on a chemical level through formal education, Jodie understands addiction through personal experience. She drew on her own experiential knowledge to support her peer, which allowed him to feel like she understood his experiences on a different level than clinicians.

This sentiment was echoed by other peer support workers throughout the study:
**Tyrone**: And so I think we have a lot to say, and to share, you know? From the inside [of] the experience, rather than just being told that this is what we should do, from an external point of view, y'know? It's colonization of mental health. That what you think isn't right, so this is what we're [clinical staff] going to do. Your reality is false, this is what it really is.

Tyrone described how peer supporters' knowledge comes "from the inside [of] the experience," rather than from an external point of view. Clinicians develop knowledge through professional education, which passes down extra-local disciplinary discourses which are then reinforced through practice. Tyrone suggested that the authority of clinical knowledge results in "colonization of mental health,"<sup>37</sup> whereby clinicians are granted authority to dictate the reality of peers' experiences, positioning peers' own understanding of their experiences as false or disordered.

# "Other People's Expertise Don't Compare": Discourses & Disjunctures of Professional/ISM

Compensation frameworks based on formal education also reflect broader

discourses which equate being a "professional" to having post-secondary education. As

Tyrone notes:

**Tyrone**: "Professional" [i]s only usually used around certain career paths, especially those who have post-secondary education. And coming from a[n] Indigenous background, I find that professionalism can be a very colonializing experience. You know, that only these people are considered to be knowledgeable and have expertise [...] they have knowledge that's essential and outside of that, you know, other people's expertise don't compare.

<sup>&</sup>lt;sup>37</sup> Tyrone speaks to "colonization of mental health" in relation to his Indigenous identity. I acknowledge that there is critique within the Mad movement of white people comparing their experiences of psychiatrization to colonialism (Rachel Gorman, annu saini, Louise Tam, Onyinyechukwu Udegbe, & Onar Usar, 2013). While Indigenous peoples may understand their experiences of psychiatrization as colonizing, as a white person, my experiences of psychiatrization are not. As a white settler, I take Tyrone's comments at face value, but do not analyze these comparisons further.

Tyrone described professionalism as a "colonializing experience" which dictates who has expertise, devaluing knowledges gained outside of formal education – including the knowledge that peers develop through their lived experience.

Although the peer support workers I spoke to wanted to be treated (and compensated) as professionals, many of them challenged discourses which equate being a professional to having post-secondary education. During our first focus group, Tyrone shared some of his hopes for our conversations:

**Tyrone**: I'm hoping we can have the discussion that being professional, for a peer support worker doesn't mean being clinical, and that professionalism also does not equal having a post-secondary education.

This statement reflects a disjuncture between how "professionalism" is known locally (by peer supporters) and extra-locally. Tyrone described professionalism *in contrast* to broader discourses which equate being a "professional" with having post-secondary education or working through clinical frameworks. In doing so, Tyrone outlined how the discourse of "professionalism" is known both within healthcare environments (as involving clinical approaches) and within society more broadly (as requiring post-secondary education).

The Indeed Editorial Team (2021) describes the differences between professional and non-professional jobs in Canada; whereas "a professional job is one that often needs a bachelor's, master's, or doctorate degree [...] a nonprofessional job requires little or no formal education" (paras. 2-3). This distinction echoes Tyrone's comments on how professionalism is equated with post-secondary education.

I wondered how else these peer support workers understood "professionalism." Instead of relying on clinical definitions, participants shared what being professional(s) meant to them as peer support workers. Jodie drew on her experiences accessing support to contrast her understanding of "professionalism" with how it is understood for clinicians. When she phoned a crisis line, the crisis line operator mentioned that they had some lived experience themself. Jodie asked the crisis line operator to share more about their experiences and how they got through it – when they did, Jodie felt as if they were giving her a "secret." Jodie shared that clinicians might be considered unprofessional for sharing their lived experience with clients; on the other hand, Jodie understands this disclosure as a key component of being there for her peers.

On the other hand, Tyrone described professionalism as a collective responsibility to foster environments that enable peer support workers to thrive:

**Tyrone<sup>38</sup>:** [Professionalism means] having a community and culture that oversees, upholds, and protects the values, principles and standards [of peer support] that allows us the opportunity and foundation to share our unique expertise and avoid peer drift and exploitation.

Instead of focusing on what peer support workers can do to be seen as professionals, Tyrone focused on the ways peer support workers can be recognized and supported as the professionals that they already are. He noted that professionalism means taking steps to avoid peer drift; instead of becoming more like our clinical counterparts, peer professionalism means staying true to our values, principles, and standards. He suggested that preventing peer drift can be accomplished through fostering peer culture and peer community – a responsibility shared amongst peer support workers, their clinical counterparts, and organizations as a whole.

<sup>&</sup>lt;sup>38</sup> This quote was created by merging Tyrone's comments both shared verbally and in the chat box on Zoom. These contributions were very similar but worded slightly differently, and are presented as a single quote to represent the overall message.

#### DISCUSSION

Peer support workers in this study described being underpaid through textual processes which determine salary through the minimum level of formal education required for a role, leading peer support workers to be treated as a "cheap alternative" as opposed to as professionals. Within these frameworks, education gained through lived experience is unacknowledged and unconsidered; consequently, lived experience as a form of knowledge is devalued.

The devaluing of lived experience as a form of knowledge leads the practice of peer support to be devalued as well. In addition to being underpaid, peer support workers are devalued by their colleagues through disrespectful comments which work to reinforce organizational hierarchies. Not only are peer support workers financially devalued (underpaid), but their contributions to the organization are also devalued (underappreciated).

When a psychiatrist compared peer support workers to cleaning staff, he devalued their contributions to the team. However, instead of working to position themselves above cleaning staff, peer support workers discussed at length the value of cleaning staff. This can be understood as a rejection and resistance of organizational hierarchies which position some staff as more valuable than others; instead of trying to prove their value by arguing their roles were more important than cleaning staff, peer support workers noted that everybody on the team was valuable.

Within healthcare contexts, formal education is emphasized and lived education is devalued. As a result, peer support workers may feel an expectation to gain formal education to prove their value and be treated as "professionals." However, this also raises

the possibility of peer drift, as peer support workers may adopt clinical approaches passed down through professional education.

These tensions can be understood in relation to disjunctures between how notions of education, knowledge, and professional/ism are known locally and extra-locally. While formal education is emphasized within healthcare environments, peer support workers develop knowledge through their lived experience. Likewise, discourses of professional/ism equate being a professional to having post-secondary education, whereas peer support workers define professionalism through alignment with peer values and approaches.

These peer support workers resisted dominant discourses of professional/ism by redefining what being professional means to them. Jodie referenced her experience calling a crisis line, during which the crisis line operator shared her own lived experiences – which Jodie noted may be understood as "unprofessional" for clinical workers to do. Likewise, Tyrone described how being professional involves more than just the ways that peer supporters approach their role; it also involves work on behalf of organizations to create an environment through which peer support workers can thrive and peer drift can be prevented.

#### **OPPORTUNITIES FOR CHANGE**

One way to ease these tensions is through challenging dominant discourses of professionalism which equate being a professional to having post-secondary education and working through clinical frameworks. These peer support workers recognize that their definitions of professionalism do not always align with clinical approaches. Redefining (peer) professionalism in relation to peer values and approaches and

recognizing lived experience as a form of knowledge may help ease the tensions which peer support workers face. Understanding professionalism solely through clinical frameworks creates the possibility of peer drift, as peer support workers are pressured to conform to clinical frameworks of professionalism. As noted by Jodie, some aspects of peer professionalism may in fact be oppositional to clinical professionalism; what is considered "unprofessional" for clinicians may be the most professional way for peer support workers to approach their work.

Tracey and I also discussed at length different strategies for having lived experience recognized by compensation frameworks, in order to increase the salaries of peer support workers and better represent their contribution to organizations. We discussed how a certain number of years of lived experience could be recognized as equivalent to a degree, and how salaries could be based on years of both lived experience and practice experience as a peer support worker.

## **CHAPTER 9: VALUES WORK**

Peer support workers in this study resisted pressures towards adopting clinical approaches by drawing on the discourse of "peer drift" – which describes a shift away from peer values and approaches toward those of their clinical counterparts (Alise de Bie, 20202; World Health Organization, 2019). They resisted ruling relations which promote freely sharing information within a circle of care, and discussed how peer support provided through lived experience was devalued by the prioritization of formal knowledge in healthcare settings.

In the following section, I explore Tyrone's suggestion that peer drift can be minimized through fostering peer culture and enabling access to peer community. Once again, I raise Tyrone's definition of "professionalism" to ground these suggestions:

**Tyrone**: [Professionalism means] having a community and culture that oversees, upholds, and protects the values, principles and standards [of peer support] [...] that allows us the opportunity and foundation to share our unique expertise and avoid peer drift and exploitation.

Tyrone's comments refer to the work of peer supporters connecting with one another (peer community), and the work of organizations to create an environment through which lived experience is honoured and peer support is valued (peer culture).

These efforts to support peer community and culture can be understood as a form of "values work," through which peer supporters ground themselves within peer support values and approaches, and organizations work to reduce pressures that could compromise these values. Below, I describe some of the work that peer supporters, their clinical colleagues, and their organizations engage in to enable peer support workers to remain grounded in peer support values and prevent peer drift.

## "IT'S HARD BEING A LONE WOLF": EMBRACING PEER COMMUNITY

Tyrone notes how working within the mental health system can indoctrinate peer support workers and lead to peer drift:

**Tyrone:** I think that when you're in the system, the mental health system, as a peer support worker, you have to be careful of not becoming indoctrinated and experiencing peer drift. [...] One has to fight a lot for peer values, and standards and stuff like that, because the system so easily wants to move you to doing something that, that isn't peer support.

Mental health systems are dominated by clinical perspectives, which may lead to

pressures for peer support workers to adopt clinical norms such as those around

documentation practices.39

One way that peer support workers in the study worked to prevent peer drift was

through engaging in peer community. However, for peer support workers to access peer

community, organizations must work to make these supports available and provide peer

supporters with time to engage with them as a part of their role.

In the following exchange, Tyrone and Angela discuss the value of engaging in

peer community by accessing peer supervision, debriefing with peer support colleagues,

and participating in communities of practice:

**Tyrone**: Having those [supervision] conversations is also I think important to have with someone who's been a peer support worker, who understands the relationships, that you can have those [...] conversations, not just from a clinical perspective, but from a peer support perspective, and to make sure that, you know, that while I'm trying to look— protect the people I support, and the agency, I'm also trying to make sure that I'm protecting that person and supporting them in having a really great experience in that peer relationship. [...]

<sup>&</sup>lt;sup>39</sup> Described in <u>Chapter 7: Troubling Documentation Work</u>.

- Angela: Absolutely. That's why it's nice to work on a team of peer support providers, 'cause you can have those conversations [with the rest of the team].
- **Tyrone**: Yeah. I think it's also important having communities of practice, as well. Like in [my city], we have a community of practice where we all get together and have conversations about peer support.

Accessing peer supervision, debriefing with peer support colleagues, and participating in

communities of practice can serve similar functions: they allow peer support workers to

debrief and access (peer) support around their experiences providing peer support.

However, not all peer support workers have equal access to peer supervision or

debriefs with peer support colleagues. Tracey describes her experiences as a "lone wolf"

- the only peer supporter at her agency:

**Tracey**: I'm the lone wolf in my office, there are no other peer support workers, and it's hard being a lone wolf. When you're everybody else seems to have a colleague that they can chat to – and don't get me wrong, I have amazing colleagues – but I'm the only one that does the work that I do. And so, sometimes it's just nice to be with other like-minded people. [...] When you're the only one doing the work that you're doing, no one else can say, "*Oh, you know, yeah* [...] *I felt the same.*"

Although Tracey appreciates her debriefs with clinical colleagues, she is not able to debrief with other peer support workers doing the same work as her. As such, she is left without appropriate supports.

However, Tyrone describes a potential solution for peer support workers who are isolated from peer community. He describes how the mainstream mental health organization that he works for purchases services for peer supervision from another organization:

**Tyrone:** We buy from [a CSI], peer supervision and I have conversations with the peer supervisor about how to look

after myself, and do proper self-care, and how to maintain healthy relationships with my peers. And having that sort of support I think is very important. [...] Peer supervision I think is [...] another cornerstone to having great peer support professionals.

Although this organization doesn't provide peer supervision internally, they work to ensure that peer support workers have access to it elsewhere. Tyrone notes the importance of having access to peer supervision by stressing that it is a "cornerstone to having great peer support professionals." Through accessing peer supervision, Tyrone is able to discuss how he can look after himself and maintain healthy relationships with his peers.

#### "THE SYSTEM TRIES TO GRIND YOU DOWN": FOSTERING PEER CULTURE

Tyrone notes one challenge faced by peer supporters working within

institutionalized settings:

**Tyrone**: A lot of workplaces want to bring peer support in, but don't provide a peer cultural experience [...] so we can stay true to our values, and standards, and ethics. [...] The system tries to grind you down.

Here, Tyrone notes how organizations don't always do the work to create a "peer cultural experience" to enable peer supporters to remain grounded within peer support values, standards, and ethics.

Through our conversations together, I came to understand "peer culture" as referring to an environment where lived experience is honoured, and the unique approach of peer support is valued. I understand peer culture to involve the work of both organizations and staff to uphold and value the contributions of peer support.

By fostering an environment of peer culture, organizations and clinical colleagues can help prevent some of the pressures peer supporters face that lead to peer drift. As explored throughout the thesis, "the system tries to grind [peer support workers] down" through encouraging conformity to organizational (clinical) norms and devaluing their lived experience. Within these contexts, the unique values and approaches of peer supporters are not fully understood or appreciated; as a result, peer support workers face pressures toward peer drift.

Hannah described how the values of her organization aligned with those of peer support, through a focus on "wellness." When she feels tensions between her role and the expectations of the organization, she can draw on organizational values to advocate for changes in how these values are practiced. She described how the organization's value of "wellness" was connected to the peer support value of "self-determination" because allowing a peer to self-determine their own revocery journey contributes to their wellness.

Angela drew my attention to the ways that peer culture can be fostered not only through the work of organizations to align themselves with peer values, but by clinical staff as well:

Angela: I had people [clinicians] who... were there for me more than my family was. They were the ones that kept feeding me opportunities, and recommended that I take training, peer support training, like a decade or more before I even became a peer support worker. [...] And I was never judged, I was never, you know, criticized for the trauma, from my history, for my illness. You know, I mean... they were the ones that helped lead me to where I am today. [...] Just because they're not peer support workers, doesn't mean there aren't people who are doing work in the mental health field that see our value, pushed me to become a peer support worker, and, you know, were more like family than family, at times.

Angela raises an important point about how clinical staff can play an integral role in fostering an environment of peer culture. When she was accessing services, the clinicians she worked with didn't judge her for her experiences with mental illness; in fact, they were the ones that encouraged her to pursue peer support training. By doing so, these

clinicians demonstrated their belief in both the value of peer support, and in Angela's

ability to support others.

Angela also described the importance of having a manager grounded in peer support values and practices:

Angela: [Our manager is] always wanting us... to learn more, and, you know, she reiterates the core concepts of what it is that we do, and <u>why</u> these are so important, and how <u>we're</u> so important. I know that my manager feels that we're— [we] have an important role, in our, in our hospital, in our system, and in our peers' lives.

Angela's manager helps foster an environment of peer culture by reminding peer

supporters of their value and the core concepts of peer support, as well as by encouraging

their learning. In doing so, her manager stresses the value of the peer support role and

grounds peer support workers within peer values and approaches.

One way that her organization supports the learning of peer support workers is by

paying for them to take training:

Angela: [The hospital] pays for [...] all kinds of training, whether it be CBT, DBT, peer support specialization. All of these things are actually offered to us, and I feel very, very fortunate.

By investing in the professional development of peer support workers, her organization demonstrates their recognition of the value of peer support(ers). These trainings include both peer-specific training, and non-peer trainings such as cognitive-behavioural therapy (CBT) and dialectical behavioural therapy (DBT).

However, other peer supporters described being limited in the training

opportunities they were able to access through their organizations:

**Tracey**: I've stumbled across [trainings that] looked so interesting, and I can tell you how it would directly impact the work I do, but, it's been offered as either training for therapists, training for social workers, [...] and it, it doesn't expressly say peer support, so I'm not eligible.

Tracey noted that she was prevented from taking trainings because they were not explicitly geared toward a peer support audience. Despite being able to articulate the ways it would positively impact her peer support practice, the training descriptions prevented her from accessing these learning opportunities.

One reason peer support workers may be drawn to clinical trainings is due to the number of different trainings that are offered to clinicians, in contrast to the limited availability of peer-specific trainings:

**Tyrone**: There's only so [many peer-specific trainings] like, there's PeerZone, WRAP, Pathways to Recover[y], GAM — Getting Autonomy with Medications, and all of this stuff. You know? And, I don't like being boxed in, y'know. I like expanding my horizons, so I can support people on a recovery journey, and let them have the best experience possible, so that means for me, being able to access trainings that, you know... are outside the conventional understanding of trainings.

Tyrone noted that he wanted to continue his learning so that he can better support his peers. However, the limited availability of peer-specific trainings led to limitations on his professional development. In order to continue "expanding [his] horizons," he wanted to be able to explore non-peer trainings as well.

## DISCUSSION

Preventing peer drift is a collective responsibility that is shared between peer support workers, their clinical colleagues, management, and their organizations as a whole. While peer support workers must work to ground themselves within peer values through engaging in peer community, organizations must first create an environment where that is possible. Peer community can be accessed by engaging in peer supervision,

#### MSW Thesis – Calvin Prowse

debriefing with peer colleagues, and participating in a community of practice. However, peer supervision is not available at every organization; some peer support workers may be a "lone wolf" – the only peer supporter at their organization. As noted by Tyrone, organizations without peer supervisors can purchase supervision services from another peer support organization to provide peer supporters access to relevant supports.

In addition, organizations and clinical workers are responsible for fostering a peer cultural environment through which lived experience is honoured and the unique contributions of peer support workers are valued. To do so, organizations can ensure that their organizational values are aligned with peer support values. In addition to providing peer support workers with opportunities to advocate for more peer-informed approaches at an organizational level, an alignment between organizational and peer values may enable clinicians to appreciate (and be informed by) peer approaches, reducing pressures for peer support workers to adopt clinical approaches to their work.

By encouraging clients to consider becoming peer support workers when they express a desire to share their lived experience and support others, clinicians can demonstrate both their valuing of peer support and their belief in their clients. A supportive (peer) manager can also help foster peer culture through reminding peer support workers of the core concepts of peer support, reminding them of their value as peer workers, and encouraging their professional development. Lastly, organizations can foster peer culture by financing the professional development of peer support workers. Although allowing peer support workers to attend clinical trainings may raise concerns of peer drift, it is worth noting that many peer support workers in this study wanted to access clinical trainings because of the limited availability of peer-specific trainings and a desire to broaden their horizons.

## **CHAPTER 10: STITCHING THREADS TOGETHER**

This study explored how the everyday experiences of peer support workers are organized to happen as they do, and how peer support workers are "hooked into" (Janet Rankin, 2017b, p. 2) common ruling relations when working within institutionalized settings. Marjorie DeVault and Liza McCoy (2012) describe the process of Institutional Ethnography as "rather like grabbing a ball of string, finding a thread, and then pulling it out" (p. 383). To explore how the experiences of peer support workers are socially organized by ruling relations, I focused on two "threads" of the everyday work of peer supporters, their colleagues, and organizations: documentation work and de/valuing work. Additionally, I explored one of the recommendations for change brought forward by peer support workers in the study, which involved engaging in peer community and fostering organizational environments of peer culture to minimize peer drift.

In <u>Chapter 7</u>, I explored how peer support workers approach the work of documentation – reading notes, writing notes, and sharing information with colleagues. Several peer support workers shared that they did not read documentation written about their peers, out of a concern that it would bring bias into their conversations. Peer supporters approached the work of writing documentation in unique ways, by providing only minimal information, working with their peers to decide what to include, and using notes as reminders to themselves. Likewise, when they were required to share information with colleagues because of a risk their peer was in danger, they shared only the minimal amount of information necessary, and allowed their peers to direct any additional disclosures.

However, troubles emerged as a result of the disjuncture between how notions of "confidentiality" and "consent" were known by peer support workers and an extra-local text (PHIPA) which guided the work of their clinical colleagues. As a result, peer support workers were pressured to adopt organizational (clinical) norms of freely sharing health information between healthcare providers. For example, Tyrone's organization asked peer support workers to read notes about his peers, and he was asked for additional information when he told a case manager that his peer was in danger.

Peer supporters drew on a different definition of "confidentiality" to guide their work, which Tyrone referred to as "peer confidentiality."<sup>40</sup> This framework is grounded in a prioritization of the peer relationship, which requires peers to provide express consent for their information to be shared with others. Importantly, peer support is not meant to be used as a tool of institutional surveillance; as Tyrone notes, disclosures within a peer relationship shouldn't be shared outside of that relationship. Practices of peer confidentiality can be fostered on an organizational level by adopting approaches like those used at the CSI Tyrone works for, which does not require peer support workers to take notes; rather, they collect minimal information in an anonymous database which is used only for funding purposes, as opposed to collecting and sharing health information with healthcare providers.

In <u>Chapter 8</u>, I explored the ways that the work of both clinical staff and organizations devalued lived experience as a form of knowledge, and, consequently, peer support as a practice. Tracey noted that compensation frameworks in her workplace only

<sup>&</sup>lt;sup>40</sup> The concepts of "peer confidentiality," "peer community," and "peer culture" are not my own, but rather reflect the language used by Tyrone. To ensure citational justice, I encourage readers to cite these terms by crediting them to Tyrone, as opposed to myself (i.e., Tyrone Gamble, as cited in Calvin Prowse, 2022).

recognized formal education as a reason for increased pay, leaving the value of lived experience unacknowledged and resulting in peer support workers being paid less than their clinical counterparts. The lower pay requirements for peer support workers leads organizations to treat peer support as a "cheap alternative," which cause peer supporters to feel like they are not being treated as professionals. Likewise, a psychiatrist at Angela's organization devalued peer support workers' contributions to the team by comparing peer workers to cleaning staff.

These troubles emerged from a disjuncture between how ideas of "education" and "knowledge" were known locally and extra-locally. While peer support workers understood their lived experience as a form of education, it was not recognized as such by organizational compensation frameworks. This connected to broader discourses of professional/ism which equate being a professional with having post-secondary education. As a result of these ruling relations, peer support workers – such as Jodie and myself – may feel expectations to pursue post-secondary education to justify their knowledge and prove their value.

However, peer support workers understood "professionalism" differently than these dominant discourses. Jodie discussed how clinical staff may be seen as "unprofessional" for disclosing their lived experience to clients; yet, these disclosures are a core aspect of peer support practice. On the other hand, Tyrone described professionalism as a macro-level phenomenon that requires organizations to work to create environments which minimize pressures toward peer drift and allow peer support workers to (re)ground themselves within peer values and approaches.

Both of these sections indicate that the institutionalization of peer support has the potential to contribute to peer drift – both through pressures to adopt clinical norms

around documentation, and to return to school to become educated in non-peer approaches to support. In <u>Chapter 9</u>, I explore some of the suggestions raised by participants to prevent peer drift. Peer support workers worked to remain grounded in peer values by engaging in what Tyrone referred to as "peer community" – by accessing peer supervision, debriefing with peer colleagues, and participating in communities of practice.

However, not all peer support workers had equal access to peer community. Tracey described herself as a "lone wolf" (sole peer supporter) at her organization; as such, she did not have peer colleagues or supervisors to debrief with. In these situations, organizations can facilitate access to peer community by hiring more staff as both peer support workers and peer supervisors. Alternatively, organizations can follow the direction of the mainstream mental health organization that Tyrone works for, by contracting supervision services from a peer support organization.

Tyrone also noted the importance of organizations fostering "peer culture" in order to prevent peer drift. Peer support workers stressed the importance of organizations and clinical colleagues working to foster an environment where lived experience is honoured and peer support is valued. Organizations fostered this environment by adopting organizational values which align with peer values and paying for peer support workers to attend trainings, while clinicians fostered peer culture by encouraging their clients to consider becoming peer support workers themselves. Peer support managers also helped foster peer culture by reminding peer supporters of the core concepts of peer support work, allowing them to (re)ground themselves within peer values and approaches.

Below, I aim to stitch these various threads together, by considering them in relation to one another. To do so, I provide some of my overall reflections, describe the

limitations of the study, and offer a series of recommendations for peer support workers, organizations, the peer support sector as a whole, and research/ers.

#### REFLECTIONS

#### The Ruling Relations of Confidentiality & Health Privacy Legislation

As described previously, I explored how peer supporters' documentation work was shaped by discourses of confidentiality constructed within the *Personal Health Information Protection Act* (PHIPA; 2004, c. 3, Sched. A). As such, my study contributes to the work of institutional ethnographers to explicate the ruling relations behind personal health information privacy legislation.

Allyson Ion (2020) also explored these ruling relations and PHIPA within her study. However, our studies explored these with a focus on different healthcare contexts, and from a different standpoint position. Allyson's study was grounded in the standpoint of women with HIV accessing perinatal care, and their concerns with their HIV status being disclosed to healthcare workers – especially to those they did not think needed to know. Allyson described how PHIPA permitted women's HIV status to be shared openly within their circle of care, as a result of the "vague language and unspecified circumstances in which disclosure is permitted without the patient's consent" (p. 437) that does not "account for the complexities and sociopolitical nuances of HIV disclosure" (p. 438). On the other hand, my study began from the standpoint of peer support workers, and their experiences being pressured to conform to organizational norms to freely share information within the circle of care.

While Allyson's (2020) study focused on the experiences of patients, and mine focused on the experiences of (peer support) workers, these ruling relations were present

for both groups in similar ways. The ruling relations of personal health information legislation led women to be concerned that their HIV status would be disclosed, and pressured peer support workers to conform to organizational norms of disclosing detailed information about their peers – especially when their peers are thought to be a danger to themselves or others.

These ruling relations result in troubles on multiple levels: for both patients (women living with HIV) and (peer support) workers. Ironically, in both of these situations, the privacy of patients/peers is compromised by legislation tasked with the protection of the very same personal health information it allows to be disclosed without their express consent.

## Re-Thinking "Professionalism": Peer Support as an "Un/Profession"...?

Drawing on her own experiences accessing support through a crisis line, Jodie defined (peer) professionalism *in contrast* to clinical definitions. In doing so, she demonstrated how assimilating to clinical frameworks of professionalism may result in drifting away from peer approaches. While disclosing lived experiences may be understood as "unprofessional" for clinical staff, it is core to the practice of peer support.

Similarly, peer support workers engaged in documentation work in ways that varied from their clinical counterparts. While refusing to read documentation and writing/sharing only minimal information about interactions might be understood as "unprofessional" for clinical staff, for peer support workers these practices are grounded in their prioritization of the peer relationship.

I wonder what new perspectives and opportunities would emerge if we were to position peer support as an "un/profession" – a profession that draws its strength from its

*opposition* to clinical professionalism, from embracing "unprofessionalism." Such an approach aligns with the consumer/survivor history of peer support, which arose in resistance (and opposition) to professionalized notions of care. This (re)positioning of peer professionalism may help prevent peer drift by highlighting the ways in which peer and clinical work differ, and the harms of imposing clinical professionalism requirements on peer work.

### The Risks of (Re)Presenting Everyday Work as "Best Practices"

It is interesting to find that the peer support workers in this study engaged in documentation in ways that mirrored the guidelines which prompted my interest in exploring the institutionalization of peer support.<sup>41</sup> Similarly to the strategies of peer support workers in Anne Scott and Carolyn Doughty's (2012b) research which were referenced in these guidelines, peer support workers in this study also kept "minimal information about their interactions with peers [and kept] notes in a collaborative... manner" (p. 154).

Anne Scott and Carolyn Doughty (2012b) described how these approaches "challenged disciplinary uses of documentation" (p. 154) including surveillance, context which was not included in the guidelines for peer support documentation which referenced this research. Although peer support workers in the present study did not use the language of "surveillance" or "disciplinary uses of documentation" to justify their approach, they did reference ideas of peer confidentiality and a desire to protect and prioritize the peer relationship. Likewise, they noted the negative impacts of sharing

<sup>&</sup>lt;sup>41</sup> Described in <u>Chapter 1 – An Entry Point to Institutionalized Peer Support</u>.

information about a peer with colleagues without the peer's consent, which may make peers feel like they were "tricked" into sharing their experiences.

The normalization of documentation practices in peer support reflects the institutionalization of the field within medical environments where documentation is required. That is to say, the work of peer support workers in both this study and the one conducted by Anne Scott and Carolyn Doughty (2012b) must be understood in relation to the peer supporters' institutional(izing) context. When the way that work *is* done is presented as the way it *should* or *ought to be* done, the ruling relations shaping this work are obscured, and we are prevented from considering new ways work *could* be done that might better align with peer values and approaches (Alise de Bie, 2022, personal communication, in reference to David Hume's is-ought problem). This risk of moving from an *is* to an *ought* is that we risk developing peer support standards which are grounded in institutional expectations of peer support workers, moreso than peer support values and philosophies.

In the current stage of professionalization and institutionalization of peer work in Canada and beyond, the peer support sector must be cautious as to not (re)present the status quo as "best practices;" we must dare to dream bigger. Instead, we must ensure that standardizing texts discuss the reasons and reasoning – particularly values-based reasoning – behind the everyday work of peer supporters. By exploring both the pressures that peer support workers face and the reasons why they respond to them in the ways they do, we can develop a more nuanced understanding of peer work and the implications of professionalization and institutionalization. This additional context may encourage peer support workers to critically reflect on how institutional expectations mis/align with peer

values, instead of simply following rules (or "best practices") as they are presented to them.

## **LIMITATIONS**

#### From Professionalization to Institutionalization

Throughout my analysis, I came to realize that the conversations I was having with participants were moreso focused on the ruling relations of institutionalization, rather than professionalization as I had originally planned. Although processes of institutionalization and professionalization are deeply intertwined and interdependent (Trish Reay et al., 2016), our discussions were more focused on exploring the ruling relations within institutional workplace environments, rather than those arising from peer support professionalization (e.g., such as those of certification). This focus is reflected in analysis; I analyzed texts associated with peer support institutionalization (i.e., legislation, organizational compensation frameworks, discourses of professionalism), but did not attempt to analyze texts associated with peer support as a profession – as an institution itself. Although participants regularly drew on texts relating to peer support (e.g., training, peer values), these texts were not analyzed or critiqued.

### Institutional Ethnography Across Settings

Typically, Institutional Ethnography interviews participants that work in the same organization or are otherwise connected by work processes in order to reveal how their work is socially organized. I took a different approach in this study, by speaking with five peer support workers in different locations across the province working within different organizations and organizational contexts. As a result, their work processes are not

directly connected to one another, and their work is bound by different organizationspecific policies.

Instead of describing one particular set of work processes in detail, this study seeks to outline the ruling relations that peer support workers experience *in common*. Although these ruling relations may take different forms in each organization (e.g., not all peer support workers were asked to review documentation), the data reflects the variety of ways in which their work is shaped by broader ruling relations relating to discourses of confidentiality and professionalism.

While recognizing the limitations this brings to an Institutional Ethnography analysis, the diversity of local settings that were represented provides insight into how peer support workers are socially organized– how they are "hooked into" (Janet Rankin, 2017b, p. 2) a common set of ruling relations. Although these ruling relations are present for all participants, it is worth noting that the operationalization of these relations may differ; therefore, the everyday work of peer supporters should be understood as *examples* of ruling relations in action, as opposed to generalizable findings. As such, I note several instances where the experiences of peer support workers differed; for example, organizations that did not require documentation.

Although discussion with participants, reflections on my own experiences as a peer support worker, and a review of the literature appears to suggest these examples are common occurrences, they may not occur for all peer supporters working within institutionalized settings in the same way; ruling relations may take different forms. However, the ruling relations themself can be considered generalizable.

Another potential limitation of this study results from its sole focus on conducting interviews and focus groups with peer support workers. Typically, Institutional

Ethnography interviews several groups of participants who are connected by work processes. Interviewing other people that are hooked into the work of peer support workers – such as clinical colleagues, staff in human resources departments, peer supervisors/managers, and peers accessing services themselves – would allow for the connections among work processes to be explored with more detail and nuance.

### **Demographic Limitations**

Another limitation of this study is that the majority of participants (4) identified as white/Caucasian; one participant identified as Indigenous. Institutional Ethnography is focused on work and the texts that govern work, as opposed to matters relating to social identity.<sup>42</sup> As such, it would seem likely that findings may be generalizable beyond this unrepresentative sample group. At the same time, organizational polices and norms are not enforced equally; racialized participants may experience greater pressure to conform to organizational norms, and/or suffer greater consequences for resistance.

For example, drawing on the work of Tema Okun and Keith Jones, Aysa Gray (2019) notes that notions of professionalism are "heavily defined by white supremacy culture<sup>43</sup>—or the systemic, institutionalized centering of whiteness" (para. 1). Aysa Gray notes that managerial practices in the United States surveil workers who are Black or people of colour moreso than their white counterparts, under the presumption that they are "less competent and cannot be trusted with completing tasks," (para. 18) which is

<sup>&</sup>lt;sup>42</sup> Except for when identity is apparent in the work and text, such as George Smith's exploration of gay bathhouse raids by Toronto police (1988, as cited in J. L. Deveau, 2009).

<sup>&</sup>lt;sup>43</sup> Tema Okun (2021) describes the characteristics of white supermacy culture as: fear; perfectionism, one right way, paternalism, and objectivity; qualified; either/or and the binary; progress is bigger/more and quantity over quality; worship of the written word; individualism and "I'm the only one"; defensiveness and denial; right to comfort, fear of open conflict, and power hoarding; and urgency.

correlated with higher rates of employment termination. I raise this discussion to note how although the work of peer supporters may be shaped by common ruling relations, workers may be impacted differently by them. As such, peer support workers who are Black, Indigenous, or people of colour may face more pressures to conform to organizational norms and suffer more consequences for resistance.

### Geographical Limitations

Another limitation of this study is that it is focused on peer support work within a specific geographic boundary – namely, within the province of Ontario (Canada). As such, there are limits to how generalizable these findings may be to other geographical areas. Because the ruling relations of confidentiality are constructed by different legal texts in different locations, their impacts on everyday work may differ as well. However, the ruling relations of confidentiality and health information privacy is not specific to Ontario; all provinces and territories in Canada are covered by different forms of legislation with a similar goal of protecting the privacy of personal health information (Office of the Privacy Commissioner of Canada, 2018). Likewise, health information is protected in the United States by the *Health Insurance Portability and Accountability Act* (HIPAA; Office for Civil Rights, n.d.). Because these pieces of legislation are intended to serve a similar function (i.e., ensure personal health information privacy), they may operate in similar ways. However, because they contain differences in both language and content, the impacts of these ruling relations on peer support workers may differ globally.

#### **IMPLICATIONS**

### Recommendations from Study Participants

Throughout the study, participants provided several ideas for change (<u>Table 1</u>). Some of these suggestions relate to the tensions described in the study, while others relate to aspirations for peer support more broadly.

The idea to provide recipients of Ontario Works (OW) and the Ontario Disability Support Program (ODSP) with access to peer support training and employment reminded me of the connections between peer support and social assistance programs. In fact, the initial funding of consumer/survivor initiatives through the Consumer/Survivor Development Initiative (CSDI) led to 307 employees by 1992, three-quarters of which were on social assistance prior to their employment (permute, 2010). More recently, I came across information about the Krasman Centre's<sup>44</sup> *Peer Recovery Education Program*, which provides free peer support training and a paid internship to peers receiving OW or ODSP (Krasman Centre, 2022). Although I have concerns that the government would position this initiative as a way for people to get off social assistance (reducing pressure to increase social assistance funding to liveable amounts), this initiative would allow peers to enter the peer support field that may otherwise be unable to due to the training costs.

I also found the idea of a peer support union to be interesting – a couple years ago, I also found myself wondering what role unions could play in the peer support sector. Although I wasn't able to find too much information about peer support unions, I did

<sup>&</sup>lt;sup>44</sup> The Krasman Centre is a consumer/survivor initiative in Toronto.

learn about peer harm reduction workers in Vancouver that joined CUPE Local 1004 in

2021 (Smart, 2001).

Table 1: Recommendations from Study Participants

	Supporting Peer Support Work
٠	Raise awareness about the value of peer support and lived experience.
•	Modify compensation frameworks to recognize lived experience as equivalent to a degree.
•	Have agencies pay for peer support workers to receive certification through Peer Support Canada.
•	Create an initiative to provide recipients of Ontario Works (OW) or the Ontario Disability Support Program (ODSP) with free access to peer support training and employment opportunities.
•	Ensure that peer support workers have a "seat at the table" for all discussions relating to mental health, so that our perspectives can be represented.
•	Create unions for peer support workers to protect our interests and advocate on our behalf.

## **Recommendations for Peer Support Workers**

Based on the results of this study, I have developed a variety of recommendations

for peer support workers (Table 2). These relate to understanding and responding to the

tensions peer support workers may face while working in institutionalized settings and

preventing peer drift.

Table 2: Recommendations	for Peer	· Support	Workers
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Preventing	Peer	Drift
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• Be aware of the tensions you might face when working in institutional settings. This research has explored some tensions in relation to documentation work and the devaluing of peer support work. However, you can learn about other possible tensions by reading other research or talking to other peer support workers. By knowing what pressures you may face in the role, you can think through how you might respond to them beforehand.

- **Resist/refuse work that does not align with peer values & approaches** (when possible). To defend your decisions, you may find it helpful to draw on peer values, peer confidentiality, your own lived experiences, or well-known documents about peer support.
- Recognize that PHIPA allows for information to be shared between healthcare providers on the basis of implied consent, but that this consent can be "expressly withheld or withdrawn" (c. 3, Sched. A, s. 20 (2)). However, this does not apply when "the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm" (i.e., when a peer is considered to be a danger to themselves or others; s. 40 (1)).
- **Practice through a lens of "peer confidentiality."** This framework prioritizes the peer relationship, and centres the interests of peers over the instituion. Participants in this study practiced peer confidentiality by allowing their peers to decide what information is shared with other staff and by not reading case notes about their peers. When writing documentation about their peers, they included only minimal information and/or worked with their peers to decide what to include.
- Engage in peer community to remain grounded in peer values and avoid peer drift. Engaging in peer community can include accessing peer supervision, debriefing with other peer support workers at your agency, or joining a community of practice.
- Be cautious when engaging in trainings geared toward a clinical audience. Because these trainings likely operate through clinical frameworks, they may create the possibility of peer drift. If you do engage in clinical trainings, debriefing with other peers may help you reinterpret what you learn through a peer lens.

Recommendations for Organizations & Clinical Workers

I have developed two lists of recommendations for organizations that offer peer

support services, as well as clinical workers. The first set of recommendations (Table 3)

revolve around enabling peer support workers to engage in peer community.

 Table 3: Recommendations for Organizations – Enabling Peer Community

	Facilitating Peer Community
•	Hire a team of peer support workers instead of just one. Hiring several
	peer support workers will allow them to debrief with one other. Being a "lone wolf" can make peer supporters particularly vulnerable to pressures from clinical staff which contribute to peer drift.

- **Provide peer support workers with access to peer supervision**, either in-house or by contracting supervision services from a peer support organization in your area. This will ensure that peer support workers have a space to debrief situations with someone else coming from a peer perspective. Clinical staff cannot provide peer supervision, even if they have their own lived experience. Peer support is about more than just lived experience, and peer supporters need supervision by someone who fully understands and appreciates the unique values and approaches we bring.
- Encourage and pay peer support workers to participate in communities of practice. Communities of practice allow peer supporters from different agencies to connect, debrief, share ideas, learn from/with one another, and (re)ground themselves within peer values. Providing dedicated time for peer support workers to engage in a community of practice and paying them to do so will help them stay grounded within peer values.

The second set of recommendations (Table 4) for organizations and clinical

workers revolve around fostering peer culture at the agency, by creating an environment

where lived experience is honoured and peer support is valued.

 Table 4: Recommendations for Organizations – Fostering Peer Culture

## **Fostering Peer Culture**

- Increase peer support worker salaries and recognize lived experience as a form of education. This will allow the salaries of peer support workers to better reflect their contributions to the organization.
- Reduce or eliminate organizational pressures for peer support workers to engage in clinical practices, such as sharing detailed information about their peers with other healthcare providers. Peer support involves a unique approach and system of values, which may conflict with clinical norms. Requiring peer support workers to adopt clinical approaches can contribute to peer drift.
- Educate staff about the unique values and approaches of peer support, and the distinctions between clinical and peer work. By learning about peer support, clinicians will be better able to appreciate the value they bring to the team. As a result, they may be less likely to make disrespectful comments about peer support workers or encourage them to adopt clinical norms which contribute to peer drift.
- Recognize the importance of peer confidentiality, and that peer support isn't intended as a way to "discover [someone's] secrets" so

**they can be shared with the team.** Instead of asking peer supporters to write detailed case notes about their peers, you could implement an anonymous database which only collects minimal information for funding purposes.

- Adopt organizational values which align with peer support values. This may minimize tensions between peer and clinical staff, promote a greater appreciation of peer roles, and enable peer support workers to defend their work as grounded in peer values.
- **Invest in the professional development of peer support workers** by paying for them to attend trainings, including peer-specific training. Peer support workers should not be encouraged to take trainings for the purposes of adopting clinical approaches however, some peer support workers may want to take clinical trainings to continue their learning. Support peer supporters in debriefing clinical trainings with other peer support workers, in order to reinterpret the training through a peer lens. These debriefings can help protect against peer drift.
- Encourage clients to consider becoming a peer support worker if they express a desire to share their lived experience and support others. This demonstrates both the clinician's belief in the value of peer support, and the ability of their clients to support others.

Recommendations for the Peer Support Sector

Below, I describe three recommendations for the peer support sector as a whole

(<u>Table 5</u>).

Table 5: Recommendations for the Peer Support Sector

	Preventing Peer Drift
•	Understand that professionalism does not mean having post-secondary education or conforming to clinical norms. Instead, peer support workers are redefining (peer) professionalism in ways that may oppose clinical definitions. As such, being "professional" for a peer support worker may involve approaches that are deemed "unprofessional" for clinical workers.
•	Instead of using descriptions of how peer support workers approach their work to develop "best practices," explore the context and rationale for why they do things in this way. The way things are done may not reflect the way peer
	support workers feel they <i>should</i> be done. Instead, it is important to note how
	these practices are shaped by institutional forces (e.g., documentation
	requirements). By sharing about the tensions peer support workers face and how

they manage them, peer support workers will learn to approach situations in a critically reflective way.

• Develop trainings and other educational opportunities exploring the implications of the law on peer support work. For example, it may be helpful to develop trainings related to PHIPA and the disclosure of personal health information. In particular, it may be helpful to explore when peer support workers are required to disclose when their peers are considered to be a danger to themselves or others.

# Recommendations for Research/ers

Lastly, I provide recommendations for future research surrounding peer support

professionalization and institutionalization (Table 6).

# Table 6: Recommendations for Research/ers

## **Explore Professionalization & Institutionalization**

- Explore the impacts of peer support professionalization, as well as institutionalization. In my review of the literature, it seems that there has been more research on the impacts of institutionalization on peer support than professionalization. It may be helpful to conduct research focused specifically on professionalization, with an acknowledgement that these processes are deeply intertwined.
- Consider the benefits of Institutional Ethnography for research on peer support work. Institutional Ethnography allows researchers to analyze institutions while remaining grounded in the experiences of peer support workers. It also aims to generate knowledge that is useful to participants in understanding and navigating their everyday lives.
- Explore the ruling relations behind reporting information when a peer is in danger. PHIPA (2004, c.3, Sched. A) allows information to be shared without the peer's express consent when "the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm" (i.e., when a peer is thought to be a danger to themselves or others; s. 40 (1)). However, this reporting requirement is also likely shaped by policies which may differ between organizations.
- Explore concepts of peer professionalism, peer confidentiality, peer community, and peer culture. These concepts may provide additional insight into how the work of peer supporters are shaped by processes of institutionalization and professionalization and provide direction on how tensions related to these processes can be navigated.

#### CONCLUSION

This study explored how the everyday work of institutionalized peer support is shaped by ruling relations, through a series of four (peer support) focus groups and interviews with five peer support workers in Ontario. By exploring peer supporters' approaches to writing, reading, and verbally sharing information about their peers ("documentation work"), I discovered how their experiences and "felt troubles" are shaped by notions of (clinical) confidentiality constructed in the *Personal Health Information Protection Act* (PHIPA; 2004, c. 3, Sched. A). I also explored the work of organizations and clinicians which devalued both lived experience as a form of knowledge and peer support as a practice ("devaluing work"). In doing so, I discovered how these experiences are shaped by dominant discourses of "professional/ism" which equate being a professional to having post-secondary education and operating through clinical frameworks.

Lastly, I described the work that peer support workers, clinicians, and organizations (can) engage in to ground peer support(ers) within peer values and approaches ("values work"). One peer support worker suggested that peer community and peer culture can help peer supporters avoid peer drift and exploitation. Peer support workers in the study engaged in peer community by accessing peer supervision, debriefing with peer colleagues, and participating in communities of practice. Organizations and clinical colleagues can foster peer culture by creating an environment where lived experience is honoured and peer support is valued.

Drawing from these suggestions and the findings of the study, I provide recommendations for peer support workers, organizations and clinical workers, the peer support sector as a whole, and research/ers. These recommendations focus on minimizing

the tensions peer support workers face in institutionalized environments, fostering peer culture and enabling access to peer community, and developing a deeper understanding of processes of peer support institutionalization and professionalization.

### REFERENCES

- Adame, A. L. (2014). "There needs to be a place in society for madness": The psychiatric survivor movement and new directions in mental health care. *Journal of Humanistic Psychology*, 54(4), 456–475. <u>https://doi.org/10.1177/0022167813510207</u>
- Adams, W. E. (2020). Unintended consequences of institutionalizing peer support work in mental healthcare. *Social Science and Medicine*, 262, 1–8. <u>https://doi.org/10.1016/j.socscimed.2020.113249</u>
- Bakshi, S. (2021). Peer support as a tool for community care: "Nothing about us, without us." *Columbia Social Work Review*, 19(1), 20–43. <u>https://doi.org/10.52214/cswr.v19i1.7602</u>
- Boschma, G., & Devane, C. (2019). The art of peer support: work, health, consumer participation, and new forms of citizenship in late twentieth-century mental health care in British Columbia. *BC Studies: The British Columbian Quarterly*, 202, 65–97. https://doi.org/10.14288/bcs.v0i202.190414
- Burstow, B. (Ed.). (2016). *Psychiatry interrogated: An institutional ethnography anthology*. Palgrave Macmillan. <u>https://doi.org/10.1007/978-3-319-41174-3</u>
- Campbell, J. (2005). The historical and philosophical development of peer-run support programs. In S. Clay (Ed.), *On Our Own, Together* (1st ed., pp. 17–66). Vanderbilt University Press.
- Campbell, M., & Gregor, F. (2002). *Mapping social relations: A primer in doing institutional ethnography*. University of Toronto Press.
- Cavoukian, A., & Rossos, P. G. (2009). *Personal health information: A practical tool for physicians transitioning from paper-based records to electronic health records*. <u>https://www.ipc.on.ca/wp-content/uploads/Resources/phipa-toolforphysicians.pdf</u>
- Chamberlin, J. (1990). The Ex-Patients' Movement: Where we've been and where we're going. *The Journal of Mind and Behaviour*, *11*(3/4), 323–336. <u>https://www.jstor.org/stable/43854095</u>
- Chamberlin, J. (2012a). A patient's view of the mental health system. In *On our own: Patient-controlled alternatives to the mental health system* (2nd ed., pp. 3–21). The National Empowerment Center, Inc. (Original work published 1978)
- Chamberlin, J. (2012b). Consciousness Raising. In *On our own: Patient-controlled alternatives to the mental health system* (2nd ed., pp. 63–85). The National Empowerment Center, Inc. (Original work published 1978)
- Chamberlin, J. (2012c). Inside the Mental Patients' Association. In *On our own: Patientcontrolled alternatives to the mental health system* (2nd ed., pp. 149–182). The National Empowerment Center, Inc. (Original work published 1978)

- Chamberlin, J. (2012d). *On our own: Patient-controlled alternatives to the mental health system*. National Empowerment Center, Inc. (Original work published 1978)
- Cupit, C., Rankin, J., & Armstrong, N. (2021). Taking sides with patients using institutional ethnography. *Journal of Organizational Ethnography*, *10*(1), 21–35. https://doi.org/10.1108/JOE-12-2019-0048
- Cyr, C., Mckee, H., O'Hagan, M., & Priest, R. (2016). *Making the case for peer support: Report to the Peer Support Project Committee of the Mental Health Commission of Canada* (2nd ed.). Mental Health Commission of Canada. <u>https://www.mentalhealthcommission.ca/wp-content/uploads/drupal/2016-</u> <u>07/MHCC\_Making the Case for Peer\_Support\_2016\_Eng.pdf</u>
- Dalmer, N. K. (2021). Mapping ruling relations: Advancing the use of visual methods in institutional ethnography. In P. C. Luken & S. Vaughan (Eds.), *The Palgrave Handbook of Institutional Ethnography* (pp. 81–97). Palgrave Macmillan. <u>https://doi.org/10.1007/978-3-030-54222-1</u>
- Daya, I., Hamilton, B., & Roper, C. (2020). Authentic engagement: A conceptual model for welcoming diverse and challenging consumer and survivor views in mental health research, policy, and practice. *International Journal of Mental Health Nursing*, 29(2), 299–311. <u>https://doi.org/10.1111/inm.12653</u>
- de Bie, A. (2022). Respectfully distrusting 'Students as Partners' practice in higher education: applying a Mad politics of partnership. *Teaching in Higher Education*, 27(6), 717–737. <u>https://doi.org/10.1080/13562517.2020.1736023</u>
- de Bie, A., Rothwell, C., Prowse, C., Yogendran, V., Douglass, M., & Green, T. (2021). What has Mad student community meant to us? Mourning Mad losses as methodology and praxis [Manuscript in preparation].
- DeVault, M. L. (1996). Talking back to sociology: Distinctive contributions of feminist methodology. *Annual Review of Sociology*, 22, 29–50. <u>https://www.jstor.org/stable/2083423</u>
- DeVault, M. L. (2006). Introduction: What is Institutional Ethnography? *Social Problems*, 53(3), 294–298. <u>https://www.jstor.org/stable/10.1525/sp.2006.53.3.294</u>
- DeVault, M. L., & McCoy, L. (2012). Investigating ruling relations: Dynamics of interviewing in institutional ethnography. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The SAGE handbook of interview research: The complexity of the craft* (pp. 381–395). SAGE Publications, Inc. https://doi.org/10.4135/9781452218403.n27
- Deveau, J. L. (2009). Examining the Institutional Ethnographer's toolkit. *Socialist Studies/Études Socialistes*, 4(2), 1–20. <u>https://doi.org/10.18740/S4F60Z</u>
- Emerick, R. E. (1996). Mad liberation: The sociology of knowledge and the ultimate civil rights movement. *The Journal of Mind and Behaviour*, *17*(2), 135–159. https://www.jstor.org/stable/43853695
- Everett, B. (1994). Something is happening: The contemporary consumer and psychiatric survivor movement in historical context. *The Journal of Mind and Behaviour*, 15(1 & 2), 55–70. <u>https://www.jstor.org/stable/43853632</u>
- Fabris, E. (2013). Mad success: What could go wrong when psychiatry employs us as "peers"? In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad Matters: A critical reader in Canadian Mad studies* (pp. 130–139). Canadian Scholars' Press Inc.
- Faulkner, A. (2017). Survivor research and Mad Studies: the role and value of experiential knowledge in mental health research. *Disability and Society*, 32(4), 500–520. https://doi.org/10.1080/09687599.2017.1302320
- Foo, Y. Y., Tan, K., Xin, X., Lim, W. S., Cheng, Q., Rao, J., & Tan, N. C. K. (2021). Institutional ethnography – A primer. *Singapore Medical Journal*, 62(10), 507–512. https://doi.org/10.11622/smedj.2021199
- Gorman, R., saini, a., Tam, L., Udegbe, O., & Usar, O. (2013). Mad People of Colour: A manifesto. Asylum Magazine, 20(4), 27. https://asylummagazine.org/wpcontent/uploads/2019/09/Asylum-20.4-2013-Mad-in-Toronto\_compressed.pdf
- Gray, A. (2019, June 4). *The bias of "professionalism" standards*. Stanford Social Innovation Review. https://ssir.org/articles/entry/the\_bias\_of\_professionalism\_standards
- Hervey, N. (1986). Advocacy or folly: The Alleged Lunatics' Friend Society, 1845–63. *Medical History*, 30(3), 245-275. <u>https://doi.org/10.1017/S0025727300045701</u>
- Indeed Editorial Team. (2021, September 7). *Nonprofessional vs. professional jobs in Canada*. <u>https://ca.indeed.com/career-advice/finding-a-job/nonprofessional-vs-professional-job</u>
- Information and Privacy Commissioner of Ontario. (2015). *Frequently asked questions: Personal Health Information Protection Act*. <u>https://www.ipc.on.ca/wp-content/uploads/2015/11/phipa-faq.pdf</u>
- Ingram, R. A. (2016). Doing Mad Studies: Making (non)sense together. Intersectionalities: A Global Journal, 5(3), 11–17. <u>https://journals.library.mun.ca/ojs/index.php/IJ/article/viewFile/1680/1327</u>
- Ion, A. (2020). Keeping secrets, disclosing health information: An institutional ethnography of the social organisation of perinatal care for women living with HIV in Canada. *Culture, Health and Sexuality*, 22(4), 429–443. <u>https://doi.org/10.1080/13691058.2019.1604996</u>

- Jones, M., & Pietilä, I. (2020). Alignments and differentiations: People with illness experiences seeking legitimate positions as health service developers and producers. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 24(3), 223–240. <u>https://doi.org/10.1177/1363459318800154</u>
- Joseph, A. J. (2013). Empowering alliances in pursuit of social justice: Social workers supporting psychiatric-survivor movements. *Journal of Progressive Human Services*, 24(3), 265–288. <u>https://doi.org/10.1080/10428232.2010.540748</u>
- Kearney, G. P., Corman, M. K., Hart, N. D., Johnston, J. L., & Gormley, G. J. (2019). Why institutional ethnography? Why now? Institutional ethnography in health professions education. *Perspectives on Medical Education*, 8(1), 17–24. <u>https://doi.org/10.1007/s40037-019-0499-0</u>
- Krasman Centre (2022). Peer support training and education. https://krasmancentre.com/what-we-do/peer-support-training-education/
- LeBlanc, S., & Kinsella, E. A. (2016). Toward epistemic justice: A critically reflexive examination of "sanism" and implications for knowledge generation. *Studies in Social Justice*, *10*(1), 59–78. <u>https://doi.org/10.26522/ssj.v10i1.1324</u>
- Mad Pride Hamilton, Hamilton Mad Students' Collective (2014). *This insane life: Mad students edition* (Alise de Bie, Ed.). <u>http://hdl.handle.net/11375/25051</u>
- McDowell, T., & Ferdosi, M. (2021). The impacts of the Ontario Basic Income Pilot: A comparative analysis of the findings from the Hamilton region. *Basic Income Studies*, 16(2), 209–256. <u>https://doi.org/10.1515/bis-2020-0034</u>
- Mead, S. (2019). Intentional Peer Support Core Materials [Training workbook].
- Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal*, 25(2), 134–141. <u>https://doi.org/10.1037/h0095032</u>
- Menzies, R., LeFrançois, B. A., & Reaume, G. (2013). Introducing Mad studies. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad studies* (pp. 1–22). Canadian Scholars' Press Inc.
- Mingus, M. (n.d.). *About*. Leaving Evidence. <u>https://leavingevidence.wordpress.com/about-2/</u>
- Morrow, M. (2013). Recovery: Progressive paradigm or neoliberal smokescreen? In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad studies* (pp. 323–333). Canadian Scholars' Press Inc.
- Nelson, G., Janzen, R., Trainor, J., & Ochocka, J. (2008). Putting values into practice: Public policy and the future of mental health consumer-run organizations. *American Journal of Community Psychology*, 42(1–2), 192–201. https://doi.org/10.1007/s10464-008-9191-y

- Ng, S. L., Bisaillon, L., & Webster, F. (2017). Blurring the boundaries: using institutional ethnography to inquire into health professions education and practice. *Medical Education*, *51*, 51–60. <u>https://doi.org/10.1111/medu.13050</u>
- Office for Civil Rights. (n.d.). *Summary of the HIPPA privacy rule*. Retrieved September 15, 2022, from <u>https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html</u>
- Office of the Privacy Commissioner of Canada. (2018, January 31). *Summary of privacy laws in Canada*. <u>https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/02\_05\_d\_15/</u>
- Okun, T. (2021). *White supremacy culture still here*. https://drive.google.com/file/d/1XR\_7M\_9qa64zZ00\_JyFVTAjmjVU-uSz8/view
- Peer Support Accreditation and Certification Canada. (2016). *National certification handbook* (3rd ed.). <u>https://peersupportcanada.ca/wp-</u> <u>content/uploads/2019/06/Certification\_Handbook\_v3-ENG.pdf</u>
- Peer Support Canada. (n.d.-a). CMHA and Peer Support Canada redraw partnership. https://peersupportcanada.ca/
- Peer Support Canada. (n.d.-b). *Peer support certification*. <u>https://peersupportcanada.ca/wp-</u> <u>content/uploads/2019/06/Information\_on\_Peer\_Support\_Canada-ENG-1.pdf</u>
- Peer Support Canada. (2022). *Peer Support Canada strategic plan 2022 2027*. <u>https://peersupportcanada.ca/wp-content/uploads/2022/09/Peer-Support-Canada-Strategic-Plan.pdf</u>
- Perceval, J. (1851). Treatment of the insane. *Provincial Medical and Surgical Journal*, 15(24), 665–666. <u>https://www.jstor.org/stable/25493195</u>
- permute (2010, August 6). *From madhouse to our house pt. 1* [Video]. YouTube. <u>https://www.youtube.com/watch?v=gnTJYtzlVkc</u>
- *Personal Health Information Protection Act*, SO 2004, c. 3, Sched. A. <u>https://www.ontario.ca/laws/statute/04p03</u>
- Pollack, S. (2010). Labelling clients "risky": Social work and the neo-liberal welfare state. *British Journal of Social Work*, 40(4), 1263–1278. <u>https://doi.org/10.1093/bjsw/bcn079</u>
- Poole, J. M., Jivraj, T., Arslanian, A., Bellows, K., Chiasson, S., Hakimy, H., Pasini, J., & Reid, J. (2012). Sanism, "mental health", and social work/education: A review and call to action. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice, 1,* 20–36. https://journals.library.mun.ca/ojs/index.php/IJ/article/view/348

- Prowse, C. (2020). A note on madness: The confluence of case files within peer & professional "care" work [Unpublished manuscript]. *School of Social Work, McMaster University*. Submitted for Social Work 3D06: General Social Work 1.
- Prowse, C. (2021a). *Peer support documentation: Praxis or peer drift?* [Webinar]. Ontario Peer Development Initiative. <u>https://vimeo.com/580814974</u>
- Prowse, C. (2021b, December 1). Peer support professionalization: Praxis or peer drift? [PowerPoint presentation]. Flash presentations: Critical disability research & teaching cluster, McMaster University.
- Prowse, C. (2022). Resisting carceral conceptualizations of suicide response [Unpublished manuscript]. *School of Social Work, McMaster University*. Submitted for Social Work 700: Critical Approaches to Practice and Leadership.
- Rankin, J. (2017a). Conducting analysis in institutional ethnography: Analytical work prior to commencing data collection. *International Journal of Qualitative Methods*, *16*(1), 1–9. <u>https://doi.org/10.1177/1609406917734484</u>
- Rankin, J. (2017b). Conducting analysis in institutional ethnography: Guidance and cautions. *International Journal of Qualitative Methods*, 16(1), 1–11. <u>https://doi.org/10.1177/1609406917734472</u>
- Reaume, G. (2002). Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients' activism in North America. *International Journal of Law and Psychiatry*, 25(4), 405–426. <u>https://doi.org/10.1016/S0160-2527(02)00130-9</u>
- Reaume, G. (2003). Consumer/survivor movement in promoting patients' rights in Ontario, 1977 to present. In *Mental Health and Patients' Rights in Ontario: Yesterday, Today and Tomorrow – 20th Anniversary Special Report* (pp. 50–52). Psychiatric Patient Advocate Office. <u>https://web.archive.org/web/20100821145424/www.ppao.gov.on.ca/pdfs/pub-ann-2002.pdf</u>
- Reay, T., Goodrick, E., & Hinings, B. (2016). Institutionalization and professionalization. In E. Ferlie, K. Montgomery, & A. R. Pedersen (Eds.), *The Oxford handbook of health care management*. (Vol. 1). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780198705109.013.1
- Roennfeldt, H., & Byrne, L. (2021). Skin in the game: The professionalization of lived experience roles in mental health. *International Journal of Mental Health Nursing*, 30(S1), 1445–1455. <u>https://doi.org/10.1111/inm.12898</u>
- Sayles, M., with de Bie, A. (2018, February 4). *Open ACCESSibility: An illustrated story* of disability advocacy. Flex Forward Educational Resources Blog. <u>https://macblog.mcmaster.ca/flexforwardresource/2019/02/04/open-accessibility-an-</u> <u>illustrated-story-of-disability-advocacy/</u>

- Scott, A., & Doughty, C. (2012a). Care, empowerment and self-determination in the practice of peer support. *Disability & Society*, 27(7), 1011–1024. https://doi.org/doi: 10.1080/09687599.2012.695578
- Scott, A., & Doughty, C. (2012b). "Confronted with paperwork": Information and documentation in peer support. *Journal of Mental Health*, 21(2), 154–164. <u>https://doi.org/10.3109/09638237.2011.638002</u>
- Smart, A. (2021, January 19). Peer support workers on front lines of overdose crisis in Vancouver set to join union. CBC. <u>https://www.cbc.ca/news/canada/britishcolumbia/peer-support-union-1.5879840</u>
- Smith, D. E. (1978). 'K is mentally ill': The anatomy of a factual account. *Sociology*, *12*(1), 23–53.
- Smith, D. E. (1997). Comment on Hekman's "Truth and method: Feminist standpoint theory revisited." Signs: Journal of Women in Culture and Society, 22(2), 375–381. <u>https://doi.org/10.1086/495164</u>
- Smith, D. E., & David, S. J. (Eds.). (1975). Women look at psychiatry. Press Gang Publishers. https://archive.org/details/womenlookatpsych0000unse/page/n3/mode/2up
- Smith, D. E., & Griffith, A. I. (2022). *Simply institutional ethnography: Creating a sociology for people*. University of Toronto Press.
- Smith, P. (2017). Defining disability studies and its intersection with madness. *Disability Studies Quarterly*, *37*(3). <u>https://doi.org/10.18061/dsq.v37i3.5940</u>
- Starkman, M. (2013). The movement. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad studies* (pp. 27–37). Canadian Scholars' Press Inc.
- Stasiulis, E., Gibson, B. E., Webster, F., & Boydell, K. M. (2022). The disjuncture between medication adherence and recovery-centered principles in early psychosis intervention: An institutional ethnography. *Society and Mental Health*, 12(1), 32–48. <u>https://doi.org/10.1177/21568693211037383</u>
- Stratford, A. C., Halpin, M., Phillips, K., Skerritt, F., Beales, A., Cheng, V., Hammond, M., O'Hagan, M., Loreto, C., Tiengtom, K., Kobe, B., Harrington, S., Fisher, D., & Davidson, L. (2019). The growth of peer support: an international charter. *Journal of Mental Health*, 28(6), 627–632. <u>https://doi.org/10.1080/09638237.2017.1340593</u>
- Sunderland, K., Mishkin, W., Peer Leadership Group, & Mental Health Commission of Canada. (2013). Guidelines for the practice and training of peer support. <u>https://www.mentalhealthcommission.ca/wp-content/uploads/2021/09/Guidelines-for-the-Practice-and-Training-of-Peer-Support.pdf</u>

- Talbot, D. (2020). Institutional ethnography and the materiality of affect: Affective circuits as indicators of other possibilities. *Journal of Contemporary Ethnography*, 49(5), 691–709. <u>https://doi.org/10.1177/0891241620943276</u>
- Tomes, N. (2006). The patient as a policy factor: A historical case study of the consumer/survivor movement in mental health. *Health Affairs*, 25(3), 720–729. https://doi.org/10.1377/hlthaff.25.3.720
- Trainor, J., Shepherd, M., Boydell, K. M., Leff, A., & Crawford, E. (1997). Beyond the service paradigm: The impact and implications of Consumer/Survivor Initiatives. *Psychiatric Rehabilitation Journal*, 21(2), 132–140. <u>https://doi.org/10.1037/h0095328</u>
- Voronka, J. (2019). The mental health peer worker as informant: performing authenticity and the paradoxes of passing. *Disability & Society*, *34*(4), 564–582. https://doi.org/10.1080/09687599.2018.1545113
- Western Massachusetts Peer Network. (2014). *Declaration of peer roles*. <u>http://www.psresources.info/declaration-of-peer-roles</u>
- Wildflower Alliance. (2013, May 26). *What makes a peer role "peer"*? <u>https://wildfloweralliance.org/what-makes-a-peer-role-peer/</u>
- Wildflower Alliance. (2019, January 17). Peer support & documentation: Yes, it's against the Massachusetts Certified Peer Specialist training and code of ethics. Here's how. <u>https://wildfloweralliance.org/peer-support-documentation-yes-it-s-against-the-massachusetts-certified-peer-specialist-training-and-code-of-ethics-here-s-how/</u>
- World Health Organization. (2019). One-to-one peer support by and for people with lived experience: WHO QualityRights guidance module. https://apps.who.int/iris/handle/10665/329643

## APPENDIX A: MAPS OF DOCUMENTATION, DE/VALUING, AND VALUES WORK

## Figure 3: Map of Documentation Work





#### Figure 4: Map of De/Valuing Work



Figure 5: Map of Values Work

## **APPENDIX B: SUMMARY FOR THE PEER SUPPORT SECTOR**

Calvin Prowse, with Angela, "Hannah," Jodie, Tracey, & Tyrone

Throughout the summer of 2022, I met with a group of five peer support workers in Ontario to explore their everyday work and the tensions they felt in relation to peer support institutionalization. This research used Institutional Ethnography to explore how the work of peer supporters is shaped by institutional forces, through exploring pieces of "text" (e.g., legislation, policies, discourse) that impact their work. This study may help peer supporters and organizations deepen their understanding of the tensions peer supporters face when working within institutionalized environments (e.g., healthcare organizations), and how to respond to them.

Below, I share a summary of the study results in three parts: documentation work (p. 136–138), devaluing work (p. 138–139), and values work (p. 139–140). Afterwards, I include three "maps" which provide a visual summary of these topics (p. 141–143). Lastly, I share the participants' suggestions for supporting peer support work, and provide recommendations for peer support workers, organizations, the peer support sector, and researchers (p. 144–146).

### **DOCUMENTATION WORK**

Some peer support workers felt troubled by expectations to read notes about their peers, and by being asked to share detailed information about a peer with clinicians. These tensions were related to how "confidentiality" is understood in healthcare legislation.

Tyrone's organization asked him to read clinical notes about his peers. Angela was not asked to read notes, but did have access to them. Both Tyrone and Angela refused to read notes written about their peers, because they were worried this might lead to preconceived ideas about their peers. Instead, they learned about their peers from what their peers shared with them directly.

These peer support workers wrote documentation in unique ways. Some of them wrote notes by only including minimal information, and by working with their peers to decide what to include. Angela used notes as reminders to herself, so that she could remember to ask about things that were important to her peers (such as an upcoming birthday party). Instead of using documentation to collect health information, she used it as a tool to deepen the peer relationship.

Tyrone did not have to take notes when he was working for a consumer/survivor initiative (CSI). Instead, he put minimal information (how long they spoke, whether it was in person or over the phone) into an anonymous database that is used for funding purposes. **Organizations can reduce tensions related to documentation by using an anonymous database for data collection purposes instead of requiring notes.** 

When a peer is thought to be a danger to themselves or others, peer supporters may be required to let their clinical colleagues know. When Tyrone told a case manager his peer was in danger, he shared minimal information – only that the peer was in danger. However, the case manager asked him for more information. Tyrone let his peers take the lead by sharing any more information themselves. This allowed his peers to have some control over the situation, preventing them from feeling hopeless and helpless.

## **Confidentiality**

These peer support workers practiced confidentiality differently than clinicians – which Tyrone called "peer confidentiality." This understanding of confidentiality can be seen in their approaches to documentation. By refusing to read notes, providing minimal information, and only sharing information with their peers' consent, these peer support workers protected their peers' privacy and self-determination. Tyrone shared that peers may feel tricked when what they tell a peer supporter is shared with the rest of the team. Peer confidentiality prioritizes the peer relationship over the demands of the system.

However, under clinical confidentiality frameworks, clinicians are entitled to detailed information about clients. The *Personal Health Information Protection Act* (PHIPA)<sup>45</sup> regulates the collection, use, and sharing of personal health information in Ontario. Because it was created to prevent communication barriers within health teams,<sup>46</sup> PHIPA allows information to be shared between service providers involved in a person's care team without a patient's express (explicit) consent, so long as consent has not been withdrawn:

A health information custodian [...] is entitled to assume that it has the individual's implied consent to collect, use or disclose the information for the purposes of providing health care [...] unless the custodian that receives the information is aware that the individual has expressly withheld or withdrawn the consent. (s. 20 (2))

When patients access healthcare services, PHIPA assumes that they have provided consent for their information to be shared. **However, it may be helpful to know that patients can withdraw their (implied) consent for information to be shared.** PHIPA helps explain how the collection, use, and sharing of personal health information becomes normalized within healthcare settings. As a result, it may help explain why peer supporters are expected to read notes about their peers and share detailed information with colleagues.

PHIPA also says that workers *may* share information (without consent) when a patient is thought to be a danger to themselves or others:

<sup>&</sup>lt;sup>45</sup> *Personal Health Information Protection Act* (PHIPA), SO 2004, c. 3, Sched. A. <u>https://www.ontario.ca/laws/statute/04p03</u>

<sup>&</sup>lt;sup>46</sup> Ann Cavoukian & Peter Rossos, P. G. (2009). *Personal health information: A practical tool for physicians transitioning from paper-based records to electronic health records*. <u>https://www.ipc.on.ca/wp-content/uploads/Resources/phipa-toolforphysicians.pdf</u>

A health information custodian may disclose personal health information about an individual if the custodian believes on reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons. (s. 40 (1))

This helps explain why peer supporters might be required to share this information with clinicians, and why clinicians ask them for more information. PHIPA says that workers *may* disclose when a patient is in danger – it does not require it (although this may be required by organizational policies). By exploring the requirements for disclosure within their workplace, peer support workers may develop a better understanding of when it is necessary to tell others when their peers are in danger.

#### DEVALUING WORK

These peer support workers described how peer support is devalued by low salaries and disrespectful comments from clinicians. These tensions were related to how ideas of education and professionalism are understood in society.

Tracey shared that her hospital determined salaries based on the minimum level of education required for the role. Because this organization only requires a high school education for peer support roles, peer supporters are paid less than their clinical colleagues who are required to have a post-secondary education. Determining salaries this way does not recognize lived experience as a form of education. As a result, both lived experience and peer support are devalued.

Tyrone shared that the low pay requirements for peer support leads organizations to hire several peer supporters instead of one clinician. He felt that peer supporters were treated as a "cheap alternative" instead of as professionals.

Angela shared a time when a psychiatrist compared peer support workers to cleaning staff. This reinforced the idea that some roles (psychiatrists) were more valuable than others (peer supporters and cleaning staff). However, instead of saying that peer support was more important, these peer supporters discussed the value of cleaning staff. Jodie noted that everybody on the team has a value.

When she first learned about peer support, Jodie noticed that all the peer supporters at the agency had a formal education. She thought that she needed more education to become a peer support worker herself, so she went back to school. Her story resonated with my own experience. I noticed that some peer support jobs required or recommended specific degrees, so I went back to school for social work to become more qualified for these roles.

### **Education & Professionalism**

These experiences relate to how knowledge and education are understood in society. It is common for only knowledge from formal education to be understood as "expertise," which devalues knowledge gained through lived experience. These ideas around education shape who society considers to be a professional. As noted by the Indeed Editorial Team:<sup>47</sup>

A professional job is one that often needs a bachelor's, master's, or doctorate degree [but] a nonprofessional job requires little or no formal education.

According to this, only jobs that require formal education are considered professions. This helps explain why peer support workers are not treated as professionals, through low salaries and disrespectful comments from colleagues. It may also explain the pressures that Jodie and I felt to return to school.

However, these peer supporters had different understandings of "professionalism." Jodie shared that clinicians may be considered "unprofessional" for sharing their lived experience with clients. However, this is a key part of peer support.

## VALUES WORK

Tyrone gave a different definition of professionalism, focused on creating environments where peer supporters can thrive:

**Tyrone**: [Professionalism means] having a community and culture that oversees, upholds, and protects the values, principles and standards [of peer support] [...] that allows us the opportunity and foundation to share our unique expertise and avoid peer drift and exploitation.

He suggests that peer community and peer culture can help minimize peer drift and the tensions peer supporters face. Preventing peer drift is a collective responsibility that is shared by peer support workers, their clinical colleagues, and organizations.

## **Peer Community**

Peer support workers can engage in peer community by discussing their experiences with other peer supporters. This allows them to ground themselves within peer values and approaches. The peer supporters in this study engaged in peer community by accessing peer supervision, debriefing with their peer colleagues, and participating in communities of practice.

However, not all peer supporters have the same access to peer community. Tracey described herself as a "lone wolf" – the only peer supporter at her agency. As a result, she didn't have access to peer supervision or other peer workers to debrief with.

<sup>&</sup>lt;sup>47</sup> Indeed Editorial Team. (2021, September 7). *Nonprofessional vs. professional jobs in Canada*. <u>https://ca.indeed.com/career-advice/finding-a-job/nonprofessional-vs-professional-job</u>

The mainstream organization Tyrone works for provides access to peer community by purchasing peer supervision services from a CSI. Other organizations can purchase peer supervision services when they cannot provide it internally.

## Peer Culture

Organizations and colleagues of peer support workers can foster peer culture by creating an environment where lived experience is honoured and peer support is valued. Hannah discussed the benefit of having organizational values which align with peer values. This can help clinicians appreciate (and be informed by) peer support perspectives, and reduce pressures for peer supporters to adopt clinical approaches to their work.

Angela noted that clinicians can foster peer culture by encouraging their clients to become peer support workers. This allows clinicians to demonstrate both the value they see in peer support, and their belief in their clients' ability to support others. She also stressed the importance of having a supportive peer manager. Her manager reminds peer supporters of their value and the core concepts of peer support, and encourages their learning.

Angela also noted that organizations can demonstrate the value they see in peer support workers by paying for them to attend trainings. However, other peer supporters said that they were only allowed to take peer support trainings. Because of the limited availability of peer-specific trainings, some peer supporters wanted to attend clinical trainings, but were not allowed to do so.

Although attending clinical trainings can contribute to peer drift, several peer supporters wanted to continue their learning by taking these trainings. They were also able to describe how these trainings would benefit their peer support work. If peer support workers attend clinical trainings, it may be helpful for them to debrief the training with other peer supporters. This would allow them to think through how they can reinterpret the training through a peer lens.

#### MAP OF DOCUMENTATION WORK



MAP OF DEVALUING WORK





RECOMMENDATIONS FROM STUDY PARTICIPANTS: SUPPORTING PEER SUPPORT WORK

- Raise awareness about the value of peer support and lived experience.
- Modify compensation frameworks to recognize lived experience as equivalent to a degree.
- Have agencies pay for peer support workers to receive certification through Peer Support Canada.
- Create an initiative to provide recipients of Ontario Works (OW) or the Ontario Disability Support Program (ODSP) with free access to peer support training and employment opportunities.
- Ensure that peer support workers have a "seat at the table" for all discussions relating to mental health, so that our perspectives can be represented.
- Create unions for peer support workers to protect our interests and advocate on our behalf.

#### RECOMMENDATIONS FOR PEER SUPPORT WORKERS: PREVENTING PEER DRIFT

- Be aware of the tensions you might face when working in institutional settings. This research has explored some tensions in relation to documentation work and the devaluing of peer support work. However, you can learn about other possible tensions by reading other research or talking to other peer support workers. By knowing what pressures you may face in the role, you can think through how you might respond to them beforehand.
- **Resist/refuse work that does not align with peer values & approaches** (when possible). To defend your decisions, you may find it helpful to draw on peer values, peer confidentiality, your own lived experiences, or well-known documents about peer support.
- Recognize that PHIPA allows for information to be shared between healthcare providers on the basis of implied consent, but that this can be "expressly withheld or withdrawn" (c. 3, Sched. A, s. 20 (2)). However, this does not apply when "the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm" (i.e., when a peer is considered to be a danger to themselves or others; s. 40 (1)).
- **Practice through a lens of "peer confidentiality."** This framework prioritizes the peer relationship, and centres the interests of peers over the instituion. Participants in this study practiced peer confidentiality by allowing their peers to decide what information is shared with other staff and by not reading case notes about their peers. When writing documentation about their peers, they included only minimal information and/or worked with their peers to decide what to include.
- Engage in peer community to remain grounded in peer values and avoid peer drift. Engaging in peer community can include accessing peer supervision, debriefing with other peer support workers at your agency, or joining a community of practice.
- **Be cautious when engaging in trainings geared toward a clinical audience.** Because these trainings likely operate through clinical frameworks, they may create the possibility of peer drift. If you do engage in clinical trainings, debriefing with other peers may help you reinterpret what you learn through a peer lens.

### RECOMMENDATIONS FOR ORGANIZATIONS: FACILITATING PEER COMMUNITY

- **Hire a team of peer support workers instead of just one.** Hiring several peer support workers will allow them to debrief with one other. Being a "lone wolf" can make peer supporters particularly vulnerable to pressures from clinical staff which contribute to peer drift.
- **Provide peer support workers with access to peer supervision**, either in-house or by contracting supervision services from a peer support organization in your area. This will ensure that peer support workers have a space to debrief situations with someone else coming from a peer perspective.
- Encourage and pay peer support workers to participate in communities of practice. Communities of practice allow peer supporters from different agencies to connect, debrief, share ideas, learn from/with one another, and ground themselves within peer values. Providing dedicated time for peer support workers to engage in a community of practice and paying them to do so will help them stay grounded within peer values.

#### **RECOMMENDATIONS FOR ORGANIZATIONS: FOSTERING PEER CULTURE**

- Increase peer support worker salaries and recognize lived experience as a form of education. This will allow the salaries of peer support workers to better reflect their contributions to the organization.
- Reduce or eliminate organizational pressures for peer support workers to engage in clinical practices, such as sharing detailed information about their peers with other healthcare providers. Peer support involves a unique approach and system of values, which may conflict with clinical norms. Requiring peer support workers to adopt clinical approaches can contribute to peer drift.
- Educate staff about the unique values and approaches of peer support, and the distinctions between clinical and peer work. By learning about peer support, clinicians will be better able to appreciate the value they bring to the team. As a result, they may be less likely to make disrespectful comments about peer support workers or encourage them to adopt clinical norms which contribute to peer drift.
- Recognize the importance of peer confidentiality, and that peer support isn't intended as a way to "discover [someone's] secrets" so they can be shared with the team. Instead of asking peer supporters to write detailed case notes about their peers, you could implement an anonymous database which only collects minimal information for funding purposes.
- Adopt organizational values which align with peer support values. This may minimize tensions between peer and clinical staff, promote a greater appreciation of peer roles, and enable peer support workers to defend their work as grounded in peer values.
- Invest in the professional development of peer support workers by paying for them to attend trainings, including peer-specific training. Peer support workers should not be encouraged to take trainings for the purposes of adopting clinical approaches however, some peer support workers may want to take clinical trainings to continue their learning. Support peer supporters in debriefing clinical trainings with other peer support workers, in order to reinterpret the training through a peer lens. These debriefings can help protect against peer drift.
- Encourage clients to consider becoming a peer support worker if they express a desire to share their lived experience and support others. This demonstrates both the clinician's belief in the value of peer support, and the ability of their clients to support others.

## RECOMMENDATIONS FOR THE PEER SUPPORT SECTOR: PREVENTING PEER DRIFT

- Understand that professionalism does not mean having post-secondary education or conforming to clinical norms. Instead, peer support workers are redefining (peer) professionalism in ways that may oppose clinical definitions. As such, being "professional" for a peer support worker may involve approaches that are deemed "unprofessional" for clinical workers.
- Instead of using descriptions of how peer support workers approach their work to develop "best practices," explore the context and rationale for why they do things in this way. The way things are done may not reflect the way peer support workers feel they *should* be done. Instead, it is important to note how these practices are shaped by institutional forces (e.g., documentation requirements). By sharing about the tensions peer support workers face and how they manage them, peer support workers will learn to approach situations in a critically reflective way.
- Develop trainings and other educational opportunities exploring the implications of the law on peer support work. For example, it may be helpful to develop trainings related to PHIPA and the disclosure of personal health information. In particular, it may be helpful to explore when peer support workers are required to disclose when their peers are considered to be a danger to themselves or others.

# RECOMMENDATIONS FOR RESEARCH: EXPLORE PROFESSIONALIZATION & INSTITUTIONALIZATION

- Explore the impacts of peer support professionalization, as well as institutionalization. In my review of the literature, it seems that there has been more research on the impacts of institutionalization than professionalization. It may be helpful to conduct research focused specifically on professionalization, with an acknowledgement that these processes are deeply intertwined.
- Consider the benefits of Institutional Ethnography for research on peer support work. Institutional Ethnography allows researchers to analyze institutions while remaining grounded in the experiences of peer support workers. It also aims to generate knowledge that is useful to participants in understanding and navigating their everyday lives.
- Explore the ruling relations behind reporting information when a peer is in danger. PHIPA (2004, c.3, Sched. A) allows information to be shared without the peer's consent when "the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm" (i.e., when a peer is thought to be a danger to themselves or others; s. 40 (1)). However, this is also likely shaped by policies which may differ between organizations.
- Explore concepts of peer professionalism, peer confidentiality, peer community, and peer culture. These concepts may provide additional insight into how the work of peer supporters are shaped by processes of institutionalization and professionalization and provide direction on how tensions related to these processes can be navigated.