

SOCIAL WORK ALUMNI EXPERIENCES WITH MENTAL HEALTH DISABILITY

BOTH AND NEITHER: NAVIGATING THE EXPERIENCES OF RECENT SOCIAL  
WORK ALUMNI WHO EXPERIENCE MENTAL HEALTH DISABILITIES AND/OR  
MADNESS

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## Abstract

While Canadian social work education has increasingly moved towards a dominantly anti-oppressive practice (AOP) approach (Larson, 2008), major gaps continue to persist in the universal application of AOP principles and values (Gormley & Quinn, 2009). This is particularly true of conceptions of mental health/illness, which have largely remained biomedical, ultimately encouraging an “us versus them” mentality between social workers and service users (Reid & Poole, 2013). This dichotomy creates challenging experiences for social work students who experience mental health disabilities and/or Madness, existing “in the hyphen” (Probst, 2014, p. 25), occupying both spaces at different or overlapping times in their lives. Despite this, there is limited research about these social work students, therefore, it was of interest to hear their stories and insights, learn more about their own identity formation, as well as their experiences in the classroom, field practicum, and early in their careers.

This project takes a critical social work theoretical approach, incorporating elements of anti-oppressive practice (AOP) and Mad studies to better understand and analyze participants’ experiences. Similarly, an eclectic methodological approach was employed, incorporating elements of critical social work research, narrative approach, anti-oppressive practice, and Mad studies. In total, four semi-structured, face-to-face interviews were completed, and a thematic analysis was conducted to highlight both the commonalities and differences between participants’ experiences. From this, seven major themes emerged including feelings of unworthiness as a barrier to accessing support and the challenges of negotiating an invisible disability. Suggestions for future directions and

next steps are presented, including mandatory mental health education for professors and students, and the creation of a more supportive and inclusive mental health culture within social work education.

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and continued to be honoured to have heard your stories and hope that this thesis is a first major step in creating meaningful change within social work education for future students to come.

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## Introduction

*“The instruments of exclusion are not visible or dramatic – men in white coats dragging people away – but quiet, insidious: We flunk out and drop out. We fail to get tenure. We take jobs as adjuncts rather than tenure-track faculty. We transfer schools; we find a way to get a job or a degree elsewhere.”* (Price, 2011, p. 6)

In introducing her book about experiencing Madness within academia, Margaret Price (2011) provides insight into the often hidden and unspoken ways students with mental health disabilities experience setbacks and obstacles, as well as the careful planning and forethought required in order to be perceived as conventionally successful. This constant calculation is not obvious and as such, the experiences, ideas, and stories from these students (myself included) remain hidden, meaning there is no place for conversation, and progress is stunted. The goal of this project is to take back the covers, and share what many social work students are going through right now, deliberately using an academic format to continue and extend a burgeoning conversation about mental health, Madness, academia, and social work education. More specifically, it is of interest to explore the (at times contradictory) duality experienced by social work students who also identify as experiencing a mental health disability and/or Madness, particularly against the backdrop of an educational experience that may, unwittingly, serve to further ingrain this dichotomy (Reid and Poole, 2013).

Social workers make up one of the largest groups of helping professionals that are involved in working with individuals and communities that experience disabilities, including mental health disabilities (Joseph, 2013). Despite this, social work’s overall

conceptualization and understanding of disability, particularly in the case of mental health disability, while evolving, remains complicated and leaves room for improvement.

Mental health is often taught and discussed in a medical, individualized, and apolitical way, which perpetuates a distinction and power difference between service providers (usually social workers) and service users (Reid and Poole, 2013). In addition, while social workers often engage in regular clinical and casework with clients who experience disability, there has been little advocacy surrounding individuals with mental health disabilities' rights and ability to also engage in social work practice as colleagues and peers (Dunn, Hanes, Hardie, Leslie, & MacDonald, 2008). Mental health disabilities affect one in five Canadians at some point in their lives (Canadian Mental Health Association, n.d.), and the reported rate of mental health issues on Canadian campuses is increasing (Lunau, 2012). Yet, there is still a great deal more discussion and research required about these students, ushering in recent calls for additional inquiry and action (Poole et al., 2012; Ennals, Fossey, & Howie, 2015), particularly since there are significant and far-reaching consequences of this limited inclusion within their personal and professional lives.

Beginning during the admissions process, students with mental health disabilities face challenges in engaging meaningfully with social work education, including uncertainty surrounding self-identification, and whether or not to seek out academic accommodations for fear of discrimination. In classes, their experiences are often not discussed in the same political or critical sense as other aspects of identity (Lacasse and Gomory, 2003), and the language and types of conversations that take place may only

work to reinforce stigmatizing beliefs and attitudes (Coriale, Larson, and Robertson, 2012). Anecdotally, my peers with mental health disabilities throughout my social work education have shared difficult stories and self-doubt – from being afraid to ask for an extension during a serious bout of depression for fear of their professors not taking them seriously, to instances of being doubted and questioned because they didn't look sick. Overall, individuals who experience disabilities are under-represented in social work education, particularly at graduate levels (CASWE, 2003), and they face similar issues in entering the workplace (Tsang, Lam, Ng, and Leung, 2000). While certain mental health crises may make it difficult to participate in full-time work, other barriers like reduced representation within education, and lack of appropriate accommodations for students, also contribute to this limitation (Shrewsbury, 2015).

Another consequence of the current situation, and the initial motivation for this project as a whole is the great loneliness that comes from feeling you're the only one suffering or falling behind, different than (and inferior to) your peers and colleagues. Experiencing mental health issues (Dinos, Stevens, Serfaty, Weich, & King, 2004), as well as the major demands of social work post-secondary education (Collins, Coffey, & Morris, 2010) can both contribute to feelings of stress and isolation. There is even less known about how these experiences overlap, let alone the added layers of complexity that come with other aspects of intersecting identities (such as race, gender, or socioeconomic status).

This isolation throughout my own post-secondary education is what initially drew my interest to this research topic. I have experienced mental health disabilities, and the

challenges that come with them since childhood, and this has not only shaped my own identity, it also encouraged my pursuit of psychology, and later, social work as a profession. However, based on the issues mentioned here (among others), I have often worried both that I would not be a good social worker, and that no matter my skill or ability, others would not perceive me as a capable practitioner because of my mental health experiences. Similarly, I have worried that I would be unable to find employment while also being out about my mental health status.

However, things are slowly beginning to change, and a new conversation is being started about the strengths and challenges facing this community. This project is intended to add to this growing dialogue. Through semi-structured interviews, my research aimed to examine both the daily experiences of recently graduated social work students with mental health disabilities/Madness as well as the larger cultural and structural factors that perpetuate these experiences. This includes discussions surrounding entering the profession, course work and field education, as well as the process of entering the workforce. The participants - living in the hyphen (Probst, 2014), in the dual identity of ‘social worker’ and person with a ‘mental health disability/Madness’ – also had the opportunity to share insight into what is working, and what changes they would like to see take place within McMaster University’s School of Social Work, as well as social work education on a broader scale.

## Literature Review

### Social Work and Disability

Social work has always had a complex – and at times contradictory – relationship with disability, both as an area of study and in practice, particularly for those whose lives are personally affected by disability (Meekosha & Dowse, 2007). In a historical review of social work and disability, for example, Mackelprang and Salsgiver (1996) note that while the profession has always positioned itself as having a duty to advocate for those who experience discrimination and oppression, this responsibility has not always extended itself to individuals with disabilities. Moreover, while social workers have and continue to often engage in daily clinical practice and casework with clients who experience disability, there has been little advocacy or discussion surrounding this group's right to also engage in social work practice as colleagues and peers (Dunn et al., 2008). This dissonance can be partially associated with the traditionally common association of people with disabilities (whether physical, mental, intellectual, etc.) as being unproductive and a burden to society, bolstered by the dominance of the biomedical model of disability throughout the 20<sup>th</sup> century and into present day (Mackelprang & Salsgiver, 1996; French Gilson & Depoy, 2002; Fudge Schormans, 2015). Within this approach, health care professionals (including social workers) are understood as the benevolent experts providing care to grateful, passive and less able recipients.

People with disabilities have experienced significant oppression, stigmatization, and marginalization in many forms, including institutionalization (L'Arche Canada, 2014), violence and increased rates of abuse (Ticoll, 1994), and exclusion from public

spaces (Kitchin, 1998). Frustrated by this oppressive arrangement and limited autonomy, Canadian disability communities began a movement towards change beginning in the late 1960s that called for the reconceptualization of disability as a facet of identity as opposed to a personal deficit (Jongbloed, 2003). In the years that followed, several major protests advocating for the rights of disabled individuals occurred across Canada, including one by blind workers who protested low wages and unsafe working conditions by leaving work for 33 days (Barnartt, 2008). In 1980, this group then joined forces with members of the Coalition of Provincial Organizations of the Handicapped (sic) to demand that Section 15 of Canadian Charter of Rights and Freedoms (which involves provision of equal rights regardless of identity) to specifically include people with disabilities as a protected group.

Since that time, there have been many steps taken towards increased advocacy and inclusion for people who experience disabilities, including the more local example of the passing of the Accessibility for Ontarians with Disability Act (AODA) in 2005, which was the result of social action by people with disabilities and their allies. The AODA mandates that accessibility standards must be met and maintained by public and private institutions throughout the province (Accessibility Ontario, n.d.). However, at the level of universities, the AODA has had limited success in effecting change (Marquis et al., 2016). Moreover, despite the AODA and other efforts to legislate for change (e.g., The Americans with Disabilities Act, United Nations Convention on the Rights of Persons with Disabilities, etc.) individuals with disabilities continue to experience barriers and limited access in their daily lives (Meekosha & Dowse, 2007). A major example of the continued challenges facing disability communities, which is of particular relevance to

this paper, is for students and recent graduates with disabilities who continue to face physical, social, and emotional barriers in their pursuit of post-secondary education (Hutcheon & Wolbring, 2012; Marquis et al., 2012; Fuller, Healy, Bradley, & Hall, 2004).

### **Disability and Post-Secondary Social Work Education**

As part of its core values, the Persons with Disabilities Caucus of the Canadian Association of Social Work Educators (CASWE) has asserted that post-secondary education is a right for all groups, including those who experience disabilities (Carter, Hanes, & MacDonald, 2012). Additionally, in recent years, more students with disabilities are choosing to pursue post-secondary education than ever before (Salzer, 2009). From this, it must be better recognized that even though students with disabilities may require certain accommodations, this does not mean they are not capable of managing, or even thriving within these settings. For example, a study of students with and without disabilities at a college in the province of Quebec (Canada) found that both groups had nearly identical grades and graduation outcomes, however, students who identified as having disabilities typically took a semester longer to finish their coursework and maintained lighter course loads overall (Jorgensen, Fichten, Havel, Lamb, James, & Barile, 2005).

However, despite the potential for academic success for students with disabilities in university, they continue to face various barriers and obstacles throughout their pursuit of post-secondary education. While there are many examples, this may include being forced to provide medical evidence of disability in order to be eligible to receive accommodations, being forced to live within the parameters of a disability label, and

facing persistent barriers, discrimination and the ongoing use of inappropriate language from administration, professors, and peers (Hutcheon & Wolbring, 2012). For example, it was only in early 2016 that a graduate student at York University in Toronto, Canada advocated for, and eventually contributed to a landmark decision by the Ontario Human Rights Commission that no longer requires students to obtain a medical diagnosis prior to accommodating for disabilities (Zlomislic, 2016). It is particularly important to highlight that much work that still needs to be done. This is both due to the increased visibility of students with disabilities within these institutions as well as the nuanced role of university in modern times – namely, an increasingly necessary component of financial stability and professional growth, as well a means to contribute to knowledge creation and academia (Jorgensen et al., 2005).

Universities have been traditionally understood as disabling environments in multiple ways. For example, in the past, some students have reported choosing their universities not necessarily for their educational programs, but rather their physical accessibility (Hearn, Short, & Healy, 2014). Other barriers include classes that do not allow for different learning styles (e.g. not allowing lectures to be audio-recorded, lectures moving too quickly), and lack of, or difficult-to-access technological (e.g. audio recorders) and practical support on campus (Fuller et al., 2004). This can create an environment that is difficult – or even impossible – to manoeuvre, as well as encourage a culture of exclusivity. Approximately 25% of Canadians without a disability have obtained a university or college degree, as compared to 12% of Canadian individuals who identify as having a disability (Myers, MacDonald, Jacquard, & Mcneil, 2014). Post-



secondary degrees are becoming more and more required in order to find gainful employment in many sectors, and as such, individuals with disabilities who face barriers during the education process may be similarly limited when seeking a career. Moreover, being barred from higher-level jobs also limits the ability of individuals with disability to enact larger policy or social change to disrupt the status quo situation surrounding the full inclusion of the disability community within everyday life (Mikkonen & Raphael, 2010).

Finally, there is also a question of if, and how, disability is discussed within post-secondary curriculums, particularly in relevant social service and helping professions. One area of post-secondary education that has more of a direct connection to ‘disability’ – and should thus make more space for disability content – is social work education, given both the practical nature of the profession, and the role of social workers in engaging with people who have disabilities in the community. The remainder of this thesis will examine this connection between mental health disability/Madness and social work education, particularly the experiences and insights of social work students who personally live with mental health disability and/or Madness. To do this properly, however, will first require an examination of the current status of social work education in Canada, including the over-arching theoretical values.

### **The Role of Mental Health Stigma within Social Work Education**

It has been 20 years since Mackelprang and Salsgiver’s (1996) review of the history of disability and social work practice. During this time, social work education and practice has developed significantly. This is most clearly evidenced in the movement towards an increasingly foundational focus on anti-oppressive practice (AOP) as a model

for education and practice within the field (Larson, 2008). AOP, while nuanced and complex, can be understood broadly as referring to the pursuit of social justice, acknowledgement of social location, and the understanding and active deconstruction of power imbalances between individuals and groups. It challenges workers to move beyond micro-level understandings of social issues, to considering larger political and social factors, such as neoliberalism, structural racism, and poverty in affecting the experiences of individuals (Larson, 2008).

Theoretically speaking, this is understood by some to be a great move forward for the field; however, it has been argued that this approach has not been taken up unilaterally within social work (Poole et al., 2012). For example, within social work education specifically, a 2003 survey of Canadian schools of social work, conducted by the Persons with Disabilities Caucus of the Canadian Association of Social Work Educators (CASWE), found that there was a decline in the enrolment amongst social work students who identified having a disability at the graduate level of study. Specifically, 5.5% of Bachelor level students, 4.1% of Masters level students, and only 1.3% of PhD students reported having a disability (Carter et al., 2012). It should also be noted that these rates might be under-reported due to students' fear of discrimination associated with being disabled (McCloy & DeClou, 2013). Therefore, even if there are more students with disabilities in Canadian social work education than generally reported, the fact that students do not feel comfortable disclosing this information, makes plain that there are still problems to still address and that stigma might be a significant issue.

Essentially, the application of AOP principles to disability and, in particular, mental health disability has been limited in social work education. For example, Gormley and Quinn (2009) argue that an explicit statement or goal to challenge mental health stigma in particular remains absent from social work literature and from descriptions of the role social work practitioners can play in practice. Furthermore, GlenMaye and Bolin (2007) explain that mental health disability may be one of the last disabilities still associated with discrimination and stigma. While this assertion inappropriately neglects to consider the experiences of other communities, such as individuals who experience intellectual disabilities, it also emphasizes that a great deal of work is still needed. Research has noted that social work has seemingly held an allegiance to the contradictory biomedical understanding of mental health, which can have many consequences. One of these is the encouragement of an “us versus them” mentality in working with clients (Reid & Poole, 2013). This can be particularly problematic for social work students who occupy both roles – social workers and people with mental health disabilities (who may at times require/access social work services) – at different and sometimes overlapping periods in their lives.

Social workers have always played a major role in the Canadian mental health field, since its early days of development. According to a survey by Towns and Schwartz (2012), social workers are currently the third most commonly accessed professional for mental health care. However, this survey does not account certain groups of people, such as those without a fixed address or those residing in institutions or correctional facilities, which most likely resulted in an under-reporting of how frequently social work mental

health services are accessed. This also indicates that social workers are often working with communities who have mental health needs that are also more marginalized, and thus in need of more consideration. The fact that social workers play such a major role in mental health services means that social work educators hold the responsibility of preparing the next generation of practitioners to effectively address the mental health needs of their communities (Probst, Balletto, & Wofford, 2015). However, within social work academic literature, students with “psychiatric disabilities” (p. 75) are not often discussed, and when they are, it is usually in the context of assessing potential impairment or unsuitability for employment within the profession (Stromwall, 2002). As Cohen and Tseris (2014) explain so aptly: “social work holds a ‘contradictory position’ of being “simultaneously engaged in both a critique of and a participation in psychiatric hegemony” (p. 689).

Moreover, the Canadian Association of Social Work Education (CASWE)’s Standards of Accreditation (2014) do not explicitly include mental health disabilities or Madness: instead, these are presumed to be included in sections that discuss supporting diversity, social justice and disability (Singh, 2016). There still continues to be significant barriers and challenging experiences associated with being a social work student who identifies as having a mental health disability or with the label of Madness throughout the educational experience. Note that while these factors are presented as discrete categories, they are entangled – over-lapping and acting upon one another – and as such, contribute in multiple ways to the lives of social work students with mental health disabilities and/or Madness.

**Admissions and Gatekeeping.** Despite the fact that over 10% of Canadian post-secondary students report experiencing a mental health disability (Poole et al., 2012), there is still a significant amount of shame and stigma associated with admitting to this, particularly when seeking admission into post-secondary education. For example, Appleby and Appleby (2006) noted that mention of a mental health issue as part of a university application could be perceived as a “kiss of death” (p. 20), in that it would be a major deterrent in their acceptance. Moreover, in applying to social work programs, it has been found that certain traits or life experiences are favoured over others: mental health disability is understood to ultimately disadvantage students seeking admission. There have been cases where potential social work students have been forced to complete and “pass” a personality assessment prior to entry into a social work program (Sowbel, 2012). For example, the BSW program at Murray State University in Kentucky specifically required each applicant to complete a personality test to assess emotional stability (Bogol-Allbritten & Allbritten, 2000). If any “problems” were detected, students were provided with counselling to address these issues prior to be accepted into the program. This requirement insidiously implies that mental health disabilities must be identified and dealt with, and that they cannot coexist with training for a career in social work.

There have also been other specific instances of outright stigma and discrimination surrounding the inclusion of people who experience mental health disability/Madness within social work education. During a presentation on mental health disabilities and Madness within social work education, Reid and Poole (2013) reported

that an administrator from another social work program asked: “But should we really just let any psychopath into social work programs?” (p. 220). This arguably indicates that while social work is often thought of as an accepting, inclusive place, there are still major battles with internal stigma to be fought. Moreover, while many people are drawn to social work and other helping professions because of their own past difficult experiences (Goldberg, Hadas-Lidor, & Karnieli-Miller, 2015), Sowbel (2012) asserts that this motivation makes these individuals “vulnerable to failure in the field” (p. 54).

Students encounter further stigma after they are admitted into social work education programs. For example, when asked how to proceed with a student who has been identified as having mental health issues, 20% of educators surveyed by GlenMaye and Bolin (2007) stated that their most typical response would be to counsel the student into leaving the program. While perhaps extreme examples, these findings do illustrate the challenges students with mental health disabilities/Madness may face in entering social work education, independent of their academic qualifications and previous work experience. These challenges are only complicated by the fact that mental health issues can often be invisible, so that students must strategically decide how they present themselves to others (Reid & Poole, 2013). It also means beginning the ongoing process of negotiating one’s identity as a social worker within the midst of these issues, which often is required component of classroom and field placement learning.

### **Stigma and mental health disability within course curriculum**

**Biomedical focus.** Despite social work education’s growing and continued emphasis on anti-oppressive practice as a standard model for education, these ideas tend

to be limited or completely excluded in classroom settings where mental health is discussed (Holley, Stromwall, & Tavassoli, 2015). For example, Lacasse and Gomory (2003) reviewed syllabi for 71 graduate social work mental health courses, and found that most focused on topics related to the biomedical components of mental health and psychology, including diagnostic categories and potential drug treatments. For example, over 88% of syllabi examined were organized by the categories of the Diagnostic Statistical Manual (DSM), while less than a third (29.6%) included at least one reading that challenged psychiatric diagnosis. This is concerning for several reasons that are usefully outlined in Robbins' (2014) review of the role of the DSM-V in social work assessment, including the somewhat circular nature of psychiatric diagnoses, the way diagnostic categories change over time, and the limitedness of an client assessment that culminates only in a diagnostic label. In other cases, mental health courses for social work programs are often housed in separate university departments, such as psychology or social sciences, and content within these classes often lack sensitivity towards students with mental health disabilities, including the "indiscriminate use of terms of crazy or insane" (Reid and Poole, 2013, p. 217).

***Classroom culture.*** While there is not much information available about social work classrooms and mental health disability/Madness, Coriale and colleagues (2012) report that disabled students, in addition to requiring technical inclusion and accommodation, also expressed a need for genuine connection with classmates. While there was formal discussion about treating clients with disabilities with respect and kindness, students reported that their peers did not try to engage with them, and that they

often felt invisible. Reid and Poole (2013) provide a thorough look into the daily experiences of social work students with a mental health disability, by interviewing several participants at an anti-oppressive school of social work in Southern Ontario. While only a preliminary project, it sheds some light onto some usually hidden experiences. For example, students reported having mixed reactions in disclosing their diagnoses and other struggles: some were hesitant as some of their professors interpreted mental health concerns as an excuse to receive special treatment, while others reported that their peers had overall been quite supportive.

Belch (2011) emphasizes the important distinction between inclusion practices that are legally mandated, and the more tangible, daily efforts that promote integration and welcome students with mental health disabilities to share in classroom/university experiences. These may include overlooked strategies such as ensuring an ASL interpreters are available in classrooms and extracurricular events (OCADU, 2013), as well as designating quiet and welcoming spaces on campus. Essentially, this echoes the sentiment presented thus far – just because there are formal policies, good intentions and mission statements in place does not always mean that these are enough to create meaningful change. While there is definitely a need for formal structure and policies (Belch, 2011), it is the additional smaller actions and environmental factors that may create a more welcoming environment for students with a mental health disability/Madness.

***Support and accommodations.*** In a study examining experiences of depression and help-seeking behaviour in undergraduate social work students, Ting (2011) found that



students reported multiple reasons for not accessing support services. One major example was fear of experiencing stigma – both from others and within themselves – as well as concerns surrounding confidentiality and the quality and availability of services. This highlights some of the challenges social work students face in accessing both mental health resources and associated academic accommodations.

Moreover, GlenMaye and Bolin (2007) surveyed 71 social work educators and found that while 88% of social work programs had made accommodations, only approximately one-third had specific psychiatric disability policies. This may indicate that schools of social work are not discussing these issues enough, and thus may be unprepared to work with such students. Interestingly, there was also a positive correlation found between educators' ratings of the effectiveness of their school's disability accommodation process, and the belief that the students were employable. (It should be noted however that, on a 10-point scale, the mean response when asking educators about the employability of students with psychiatric disabilities was slightly above six, arguably indicating more work is needed to change attitudes and outcomes for students.)

**Field placements.** Field placements (also known as practicum) are both a significant and mandatory component of social work programs, including those in Canada (Bogo, 2005). Field placements can be challenging times of transition and learning for all social work students, not including the unique challenges faced by students who also identify as having a mental health disability. Social work field educators are often faced with the almost dichotomous roles of “protecting” the social work profession, while at the same time encouraging student growth and development (Sowbel, 2012). In addition,

there is a great deal of uncertainty, improper training, and lack of clear strategies, policies, and legal implications for field educators regarding students who disclose or require additional support (McAuliffe, Boddy, McLennan, & Stewart, 2012).

Moreover, social work field educators often feel worried and unsure of how to properly assess a student during practicum to ensure that they are ready for practice (Miller & Koerin, 2001). In one study with social work educators, most agreed that they had problems with and needed much improvement in identifying and assisting students who experience psychiatric disabilities (Mazza, 2015). After conducting a series of interviews with social work practicum students, Hearn et al. (2014) reported that students with disabilities face many barriers in entering the placement process, including their own apprehension, assumptions about their capability, and limited settings being offered to them. The authors also noted the importance of supervisors believing in their placement students, looking beyond their disabilities, and considering the unique strengths that their dual perspectives can provide.

### **Entering the Workforce**

Dunn and colleagues (2008) argue that it is not enough that individuals with disabilities be given an education, it is equally important that they also are able to graduate and find meaningful employment. The authors also report that for people with a variety of disabilities, finding employment is a challenging, lengthy process. In general, it has been reported that individuals who identify as having long-term mental health issues tend to have difficulty gaining status as respected, full-time, adult workers (Roets, Kristiansen, Van Hove, & Vanderplasschen, 2007).

This begins, as Shrewsbury (2015) explains, when students with disabilities remain underrepresented in educational programs that provide access to professional positions, such as social work. It can be argued that this process continues throughout the educational process, including difficulties in receiving academic accommodations that provide equal opportunities to succeed; difficulties in securing appropriate placements; and a lack of discussion surrounding the mental health of social workers beyond individualized notions of self-care. This continues in spite of the findings of a meta-analysis by Tsang and colleagues (2000) that despite their differences, people with psychiatric disabilities can be and often are productive, valuable employees overall, and that a variety of complex factors influence this relationship. Overall, there is limited literature available outlining how many practicing social workers experience mental health disability and/or Madness, which may be a consequence of self-stigma and limited reporting, as well as a lack of formal research focus on this community thus far.

### **Impact on “Hyphen Students”**

In struggling to find a term that aptly described the group of individuals whom I hoped to speak to for this project, I was inspired by a novel article from Probst (2014) – one of the first to examine the experiences of social work practitioners who also have been clients of social services, particularly counselling services. Probst (2014) describes this as: “...the dual experience of being clinician and client, diagnoser and diagnosed – ‘living in the hyphen’ that connects the two identities” (p. 25). In interviewing social work students who identify as Mad and/or experiencing mental health disabilities, Reid and Poole (2013) share the challenges that come from learning and working within an us-

versus-them culture cultivated in social work. Because of the way mental health is discussed formally and informally within social work classrooms and practicums, students expressed being unable to negotiate being a social worker while simultaneously being their genuine selves. Overall, with this project, I want to continue the important work started by Reid and Poole (2013). Specifically, I aim to learn more about and share the stories of social work colleagues – students and new workers – that are often not told. It is of interest to learn more about the experiences, ideas, and stories that have come from their unique perspective of living within the hyphen, being both and neither all at once.

## **Theoretical Framing**

### **Researcher's Voice: Grounding the Research Topic**

Before delving into greater detail about the structure and outcome of this project, I feel that is important that I first position myself, as a researcher and social work student, relative to this topic. I identify as a person who experiences chronic mental health disability, which has invariably influenced my academic career, as well as the professional roles I have held in the past several years. I have faced many challenges, including stigma (both from others and myself), barriers, and isolation stemming from my actual symptoms as well as existing structures that I felt did not take into account my needs or my experiences. Managing a largely invisible disability while navigating post-secondary education has been further complicated by my choice of profession – social work, which, while espousing a commitment to adopting an AOP approach continues to exclude the needs of students with mental health disabilities.

As someone who has lived with a mental health disability for most of my life, and “in the hyphen” (as Probst (2014, p. 25) describes it) for the entirety of my academic career, I feel it is my responsibility to take on the challenge of further exploring and making known what is often strategically hidden or managed for fear of repercussion. In order to achieve this my research is grounded in a critical social work approach to research that places the voices of individuals who are experiencing the study topic at the foreground, as the experts. Research is not being “done” on these individuals, but rather with them (as completely as possible, given practical constraints). This is, similarly, why

I have chosen to make my own identity clear, as it deliberately blurs the traditional lines between researchers and their subjects.

### **Critical Social Work Perspective**

In being dissatisfied with the current limited conceptualization of mental health within social work education, I chose to take a critical social work approach to the research. As Fook (2003) explains, a critical social work perspective challenges positivist notions, and works to develop ways of knowing that move beyond traditional or dominant ideals. For example, critical social work does not assume that knowledge is external to us, waiting to be discovered; rather it is constructed and interpreted socially (Campbell & Baikie, 2012), implying that each individual may reach a different conclusion. Our individual experiences, and our social, political, and cultural positionings all influence the lens through which we interpret our worlds, where the voices of those who experience greater privilege are often the ones that are heard most clearly and seen as most valid (Healy, 2005). This, in turn, gives power to certain individuals, and oppresses those who do not fit within the dominant prescribed lens of ‘normalcy’. Critical social work, therefore, challenges the assumption that any kind of deviance from prescribed norms (such as experiencing a mental health disability) is an individual deficit; rather, it is reflective of societal shortcomings to acknowledge and challenge conditions that contribute to individual suffering, such as poverty and discrimination (Alderson, 1998).

**Social constructionism.** One part of this perspective that is particularly relevant is the acknowledgement of a social constructionist theory of reality, which asserts that social problems are not objective issues to be studied and corrected but rather exist

through individuals' social interaction with them (Miller & Holstein, 1993). Social issues, therefore, cannot be comprehended or corrected through objective observation and data collection, but rather only through understanding how different individuals experience them, based on their own interpretations of reality. This approach is particularly pertinent for discussions surrounding disability, challenging the notion that mental health disability and Madness is simply a result of individual deficit (Mulvany, 2000). Rather, the social constructionist approach demands acknowledgement and analysis of the political, social, and economical conditions that oppress individuals living with a mental health disability, as well as focuses on the rights and potential for collective political power within this community. Learning more about disability through a review of the literature, as well as from my own experiences, has influenced me to pursue a critical, social constructionist framework for this research project. However, it is also equally important to consider the role of one's whole identity in experiencing mental health disabilities or Madness.

### **Anti-Oppressive Practice**

In developing the framing for this project, I felt it was also important to include theoretical and methodological guidance from a dominant approach within social work education and practice – anti-oppressive practice. Within recent years, the anti-oppressive approach has become a dominant component of social work education and practice (Clarke, Aiello, Chau, Atcha, Rashidi, & Amaral, 2012) and therefore it is important to consider how this approach has been applied to the teaching and discussion of mental health issues and the impacts of such on social work students identifying as having a mental health disability/Madness. While a complex field on its own, anti-oppressive

practice (AOP) works to address structural inequalities and power differences that exist within society, and acknowledges that the everyday experiences of individuals are shaped by their oppression, or yielding of power (Baines, 2011). AOP is also concerned with minimizing the power differences that exist, both on a large scale between communities, and on a micro-scale, between worker and clients (McLaughlin, 2005).

**Invisibility and passing.** AOP also provides another impetus to consider the role of other aspects of identity, including race, gender, age, and socioeconomic status exist in the context of a mental health disability, particularly in cases where individuals can pass as ‘normal’, and not be automatically categorized as ‘other’. There is a large amount of literature surrounding the issue of passing (appearing to belong to the dominant group) within scholarship on racism and homophobia. For example, in an article in *Everyday Feminism* magazine, Gutierrez (2014) recounts being consistently questioned by her peers about whether or not she was really Spanish, often being asked to prove it. Samuels (2003) also brings up the necessity of having to come out of the closet as a gay person, negotiating when and how, and who is a safe person to disclose to. She correlates coming out with her friend’s experience of identifying as disabled – expressing pride in this label, and wanting to share it with others despite her family’s distaste for what they see as an offensive and limiting label. In this, we also see the power that some individuals and communities feel from choosing to reclaim labels and their meaning; of major relevance to this paper are the ways that some psychiatric survivors have reclaimed the label of Madness.



## **Mad Studies**

Overall, the ideas of anti-oppressive practice, critical social work, and the reclaiming of identities culminate into the burgeoning psychiatric survivors/Mad studies movement. Given that it is still in an early stage of development, Costa (2014) explains that it's difficult to pinpoint a concise definition, but offers the following as a starting point:

“Mad studies is an area of education, scholarship, and analysis about the experiences, history, culture, political organizing, narratives, writings, and most important, the PEOPLE (sic) who identify as: Mad; psychiatric survivors; consumers; service users; mentally ill; patients, neuro-diverse; inmates; disabled – to name a few of the ‘identity labels’ our community may choose to use.” (para 3)

The first university course in Canada to critically examine the history of psychiatry from the perspective of patients was developed by Geoffrey Reaume at Ryerson University in Toronto, Canada during the early 2000s (Gillis, 2015). Since then, this academic field has continued developing and has become a respected theoretical and methodological approach, including the landmark publication of *Mad Matters: A Critical Reader in Canadian Mad Studies* in 2013. The book contains chapters written by Canadian activists and academics attempting to situate the field and connect it to multiple domains (including academia, racism, criminality, etc.), as well as attempting to determine next steps. Moreover, there are student communities developing across Canada to bring together students who experience mental health disabilities and/or Madness, including the local example of Hamilton Mad Students Collective.

Mad studies encourage highlighting and focusing on the voices of individuals with lived experiences as an alternative to the absolutes of psychiatry (Gillis, 2015), and is currently being built and developed on a foundation of “critical activism and scholarship” (LeFrancois, Menzies, & Reaume, 2013, p. 12). Mad studies follows in the footsteps of other critical schools of thought, including disability studies, while also working to carve its own place within academia. Taking a note from anti-oppressive practice, Mad studies also acknowledges the importance of race, class, gender, and other traits as they relate to mental health disabilities (Gorman, 2013). Mad Studies is however understood to be a work in progress: for example, a current struggle is negotiating the understanding of Mad studies as a radical field, that while formalized within academic institutions, continues to remain rooted in movements that spoke against those very same institutions (Reville, 2013).

Moreover, a Mad studies approach calls for critical research that – in direct contradiction to traditional models of disability research – is conducted *by* the community (people who have mental illness) rather than *on* them (Russo & Beresford, 2015). This has been a major inspiration for my own research methodology in that, as an insider, I am hoping to collect and share knowledge about people like me, from people like me, for people like me. Also taking influence from the related critical social science methodology, as explained by Neuman (1997), Mad Studies seeks both to challenge dominant norms of positivist assertions of truth, and to expand the logging of individual experiences as a catalyst for social transformation. Overall, the theoretical lenses of critical social work,

anti-oppressive practice, and Mad studies have informed this research project, as well as the way these different lenses complement and speak to each other.

## **Methodology**

### **Methodological Approach**

This qualitative research project employed an eclectic methodological approach, employing components of critical social work research, narrative approach, anti-oppressive practice, and Mad studies. In reference to the former, a guiding principle from critical social work research (and this project) is a focus on individuals' ideas and interpretations of events to create knowledge, rather than trying to decipher some kind of objective or ultimate truth from systematic observation (Neuman, 1997). Similarly along these lines, research, rather than trying to simply find answers, should have a goal of trying to create social change – a key aim of this project as well. In addition, while there was less of an emphasis on collecting participants' full stories, narrative approach's tenets for data collection and analysis were also followed. These included working to create a climate of trust, being clear about my own investment in the research topic, and taking a less structured, more conversation-based interview style (Fraser, 2004).

Moreover, from an anti-oppressive lens, it was important that the power difference between researcher and participants was acknowledged, and that steps were taken to reduce these effects, particularly during the interview (data collection) process, including member-checking strategies and engaging in respectful interviewing practices (Strier, 2007). In addition, other aspects of identity were considered in the types of questions asked, and in how interview data was analyzed and presented (Banks & Kohn-Wood, 2002). Finally, research within a Mad studies framework should be done *with* the community, and not simply be about them (Ochocka, Janzen, & Nelson, 2002): as a

member of this community, I take this last point seriously, and have done my best to both complete this project with integrity, and to include participants and their voices as fully as possible. There is a lack of content surrounding psychiatric survivors and consumers within academic research at all (Jones & Brown, 2013) therefore, even the deliberate use of “Mad” as a descriptive word for participants works to counter this gap. Overall, it should be noted that each of the guiding methodologies mentioned overlap and coincide with each other in multiple ways. While I have done my best to note which specific components from which field have guided my project, it is important to emphasize that other approaches may have also provided a similar foundational background.

### **Ethical Considerations**

The first step in conducting this project was receiving review and approval from the McMaster University Research Ethics Board (REB), which resulted in several challenges, which are of relevance given this project’s topic. First, the REB expressed concern, and perhaps misunderstanding, surrounding the selected use of the terms ‘disability’ and ‘Madness’ when referring to potential participants’ experiences, suggesting that these terms may deter individuals from participating, and that they were also potentially offensive and inappropriate. This was despite the fact that both terms are recognized as legitimate by these communities and, by some, as reclamation of identity and a moniker for their collective (Brown, 2002; Costa 2008).

The reviewers were also concerned that discussing their experiences might be ‘triggering’ and might lead to potential medical or psychiatric crises. While most likely coming from a place of genuine concern, there is research to suggest it is unfounded. For

example, Schneider (2012) described the success of The Hearing (our) Voices project, which was largely carried out by individuals with schizophrenia, and found it was both successful and demonstrated participatory research as a way to promote health equity and challenge marginalization. The concerns of the REB, however, could be understood to make sense based on the aforementioned culture surrounding mental health within post-secondary education (Hutcheon & Wolbring, 2012), which is still wrought with barriers based on biomedical assumptions about mental health (Holley et al., 2015).

In response to the REB's concerns, I familiarized myself with and made note of available emergency and crisis services on campus and within the Hamilton area, should they be required. In addition, I also highlighted to the REB that standard research ethics protocols were already in place that facilitated the participants' safety. The first was the fact that participants self-identify for study inclusion (knowing what is required), I provided regular reminders that participation in the study itself was voluntary, and finally that participants would be invited to review and edit data from their interview that would be included in this write-up. After interviews, participants would also be provided with a full list of mental health and support resources (Appendix D). After ensuring there were support services in place, this project (Protocol 2016-089) received approval from the McMaster University REB. Finally, the interview guide (Appendix C) was deliberately chosen to not include questions about mental health symptoms or traumatic events, but rather focused on recalling their daily experiences related to their social work education. This was not out of fear of triggering participants, but rather to keep in line with the theoretical and methodological principles guiding this project. In respecting participants,

and viewing them as collaborators rather than a data source, I chose to respect their autonomy and stories, by only asking them to share what they had agreed to share.

### **Participants**

In an attempt to properly respect and honour the wide range of experiences and definitions people hold regarding mental health, participants simply had to identify as experiencing mental health disability and/or Madness, whatever that meant for them. Moreover, they were required to have left McMaster University's School of Social Work no more than five years ago (2011) to ensure this project captured a current snapshot of their social work education. As a way to maintain confidentiality as well as protect the relationships I have developed this past year in the MSW program, potential individuals who were currently enrolled in the social work program at McMaster University with me were excluded. Participants were required to be located in the Greater Toronto-Hamilton Area (for logistical purposes), and be at least 18 years of age. There were no additional restrictions placed on other aspects of identity, such as gender, race, or physical ability.

In total, four participants were interviewed, two identified as male and two as female. All participants had attended McMaster University's School of Social Work between the years of 2011 and 2015. This information was collected during the interviews as part of confirming participants' preferred gender pronouns before conducting the interview. This information was collected to ensure use of appropriate language during interviews with clients, but the gender-neutral pronoun "they" is used throughout the data analysis section of this thesis as a means of protecting participants' confidentiality.

No other demographic information was collected. This choice was deliberate, and an attempt to limit the feeling of “being studied” or collecting information from participants without just reason, similar to the previously-mentioned choice of not asking about participants’ mental health symptoms or traumatic events in their past. Three participants had completed their bachelor of social work degree, while one had completed their masters degree at McMaster. Three participants had plans to enter the workforce in a social work position, and are currently involved with the application process, while the fourth has chosen to pursue another graduate degree within a different discipline.

### **Recruitment**

Study participants were recruited through a general email recruitment letter (Appendix A) sent on my behalf by the Director’s/Graduate Administrative Assistant in McMaster’s School of Social Work. This recruitment email script was sent to both the undergraduate and graduate alumni email lists, and included a copy of the Letter of Information/Consent Form as an attachment, as well as a brief note explaining the study. This recruitment method ensured the option of self-selection. Interested individuals were directed to email me.

From there, I worked with potential participants to answer any questions they had, and to set-up a date, time, and convenient location to meet. In the recruitment email, it was suggested that interviews could either take place in a private room at McMaster University’s School of Social Work (to be booked by myself) or at a public place, such as a park or coffee shop. It was explained that the latter option involved being visible within the community, and possibly overheard by others while discussing potentially sensitive or



personal topics. These options were meant to take into account both the personal comfort of each participant, and also acknowledge that mental health disability and Madness is both a sensitive topic, where disclosure can have real consequences in individuals' lives. Out of the four interviews conducted, one was held at McMaster University, while the remaining three interviews were conducted in the community, including at a local coffee shop and two Toronto university campuses.

### **Data Collection: Interview Process**

Taking a note from Mad studies and anti-oppressive research, qualitative interviews were conducted which positioned participants as the experts, allowing them to choose which experiences they shared (Russo & Beresford, 2015). To begin the interview, I reviewed the letter of information and consent form (Appendix B) with each participant, and participants were able to have any parts of the study clarified and any questions answered. This included reiterating that this was a voluntary study, and that the interview could be ended at any time, based on their own comfort level and preference. Then, two copies of the Letter of Information/Consent Form (Appendix) were completed, signed, and dated – one copy was kept by myself (stored in a locked, private filing cabinet), and the other was for the participants' reference. Interviews were recorded on my personal, password protected cellular phone, and ranged in total time from approximately 35 minutes to approximately 70 minutes. At the completion of the interview, participants also received a small token of appreciation, in the form of a gift card.

The interviews themselves were semi-structured in nature, with the Interview Guide (Appendix C) itself being constructed using components of a narrative research

framework. This included the use of open-ended questions written in plain language, and the preparation of subsequent prompting questions (Elliott, 2005), as well as asking questions that acknowledge the role of structural factors in influencing individuals' experiences and stories (Roscoe, 2009). In addition, it was very important to avoid "mining" (p. 184) during interviews for irrelevant information (e.g. about symptoms) and to share my own investment and connection to the research topic (Fraser, 2004), both during recruitment and within interviews themselves.

The content of the questions centred on participants' experiences during their social work education, including the admissions process, accessing accommodations, classroom and placement experiences, and larger questions surrounding personal and professional identity. As a departure from narrative approach, there was less of a focus on collecting whole stories from participants about a single idea or event (e.g. Ollerenshaw & Creswell, 2002). Instead, interviews took an exploratory approach, inviting participants to speak briefly on a wide variety of experiences within the educational context. The Interview Guide (Appendix C) itself was based largely within the principles of anti-oppressive research (e.g. Strier, 2006). This meant questions were aimed at uncovering instances of oppression and power within social work education, the acknowledgement of one's identity in shaping these experiences, and changes required in order to rectify instances of social injustice within social work education and universities overall.

### **Data Analysis**

**Thematic analysis.** After interviews were completed, their audio recordings were transcribed, in preparation for the process of inductive thematic analysis. From there, the

first step for analysis was simply to immerse myself within the great deal of data collected. This step, which is common for narrative approaches to research (Ollerenshaw & Creswell, 2002), involved multiple readings of interview transcripts to better grasp what ideas were brought up within and across interviews. After this immersion phase, as guided by Green and colleagues (2007), I began the process of marking and coding interview transcripts. Using my aforementioned methodological lenses (particularly anti-oppressive research), I aimed to focus on content involving personal experiences of oppression and power and connections between the individual and structural in shaping these experiences (Strier, 2006).

Continuing to use the work of Green and colleagues (2007) as a guide, I then used these codes to develop general categories that described a variety of responses within a single area, such as “course content” or “accommodations”. As opposed to remaining there, the authors suggested to move specifically to identifying *themes*, which rather than just describe, provide “interpretation” (p. 549) to the overall research question. This required the linking of categorical findings to existing literature, as well as the guiding theoretical and methodological principles – truly synthesizing the data into meaningful components. For this project specifically, this included demonstrating the ways social constructionism operated within social work education by the invisibility of mental health disability to how it is understood with post-secondary education, and how it is tied to ideas of worthiness. In addition, given Mad studies relative newness as a recognized field of study (Rowland, 2015), I thought it was important to consider how this identity had been taken up by participants, and connect this to other social factors. Overall, seven

themes, including the aforementioned ideas were captured and focused on for the analysis of this paper.

**Member checking.** In keeping with a critical social work research approach, participants were also offered the opportunity to engage in the self-checking process, in that they were sent a copy of portions of this report that included excerpts and information from their interviews for their review (Wray-Bliss, 2003). No participants requested changes. In addition, prior to the submission of this thesis for review, all four participants were emailed a draft of the findings and discussions sections and asked to respond within a week if they had any concerns about content included. Two respondents replied, one requested that a slang term she used be replaced with a less colloquial term, while the second confirmed that no changes were required. At the completion of this project, participants will also receive a brief, plain-language summary of this project, and those who indicated interest on their Letter of Information/Consent Form will also receive a full copy of their interview transcript. This is also in keeping with the theoretical framework provided by Mad Studies, particularly the tenet where research should be done for, by, and with the community (Ochocka et al., 2002). It was my intention to as accurately as possible represent and portray participants' words and ideas, even if they differed from what was said during our interviews.

## **Findings and Discussion**

For this section, I deliberately chose to combine the reporting of research findings and analysis because I felt it was most meaningful to feature participants' words alongside existing research as a way of grounding this project in the larger discussions surrounding mental health/Madness and social work education. Overall, each of the four interviews conducted provided unique and powerful insights into the lives of social work students who identify as experiencing mental health disability and/or Madness, as well as the ways these experiences shaped other aspects of their education. While these interviews were rich with experiences and ideas, several key themes came to the forefront. The themes to be addressed here include: the role of Madness, course content, peer and faculty attitudes, the challenge of invisible disability, unworthiness and seeking accommodations, and the formation of personal and professional identity. Moreover, a common thread of mental health stigma (in its many forms) weaves through and connects each of these themes, providing a starting point upon which to understand participants' stories.

### **Madness and the Reclaiming of Labels**

One of the goals of this project was to learn more about if, and how, the Mad movement contributed to participants' understanding of identities surrounding their own mental health experiences. Interestingly, of the four participants interviewed, none seemed to be strongly attached to the label of Mad. In fact, one participant had not even heard of the term or field of study prior to the interview. When I provided a brief explanation of the general tenets and reasoning behind the term, most participants seemed

neutral, but positive. For example, when one participant was briefly introduced to Mad studies, they explained:

“Um... I think I do [identify with the label of mad], which is to say I like what I’m hearing about it, but I haven’t actually taken the time to really get into it, like study anything... But in general, what I’ve heard like sort of taking the power back, in terms of being our own authors of our own experience, then absolutely if that is what it is that’s how I’d identify.”

Another participant explained that while they understood the value of the movement and the reclaiming of the Mad identity, it was not for them:

“Personally, no, I could see why some do but no... I understand why, it’s like reclaiming and stuff like that but for me personally, it just doesn’t feel like the right term for me. Just like how some people are reclaiming the word fag [sic], that to me is just not a word I would claim for myself.”

At the time of the interview, however, I did not ask the participant to further expand on why they felt this way, which is unfortunate, as it could have provided additional context for deconstructing the relationship social work students feel towards Madness. Overall, however, these different responses perhaps make sense, given Mad studies’ still-early development and positioning within academia, as well as within the more general population. As Rowland (2015) explains, Mad Studies faces a unique challenge in defining its identity as a group, as well as what it means for individuals who choose to take on the label. This may be for several, overlapping reasons, the first of which being there are so many commonplace, medical, and alternative terms used to

describe mental health disabilities that it becomes difficult to collectively agree on a singular definition. There is also a great deal of confusion and in some instances negative stigma surrounding the use of some of these various terms, including Madness and disability (as revealed in the REB process). Galinsky and colleagues (2013) report, however, the reappropriation of once stigmatizing labels can actually reduce the stigmatizing power of these once-derogatory terms over time. Therefore, more time may be required to properly assess how students feel about the reclamation of this particular term, and its reciprocal relationship with self and public stigma.

The difficult collaboration of Mad studies with the university (the movement itself is a rebellion against the structural oppression facing people with mental health disabilities – including oppression occurring in academic) is still new. In addition, the inclusion of politically based content on mental health disability/Madness in university courses is still limited (Reville, 2013). Participants reported that Mad studies and the political aspects of mental health were not brought up in any of their readings or class discussions in a significant way. It is interesting to note, then, that despite social work's dedication to social justice, these alternative understandings are not yet commonplace in Canadian social work education approaches to mental health (Stromwall, 2002; Holley et al., 2015). This idea will be further deconstructed by more closely considering how mental health is taught (including what is missing) within social work courses and discussions.

**Course Content: Moving Beyond Biomedical Approach**

I was interested in learning more about how mental health and illness was discussed within participants' social work classes – their readings, class discussions, and lectures. Overall, participants explained that mental health was mentioned and discussed in some mandatory classes, but usually in general terms and in the context of diagnoses, treatment modalities, and the therapeutic process. As one participant explained: “It was very general, and always very clinical and not personal at all...” From a critical, anti-oppressive theoretical lens, potentially rich sources of information are ignored. This includes the perspective of people with mental health disabilities, the intersection of other aspects of identity, and the use of research as a tool for social change, so that mental health disability/Madness stigma is maintained. In fact, attributing mental health disabilities solely to biomedical causes, while increasing the public's mental health literacy, has actually backfired and, in fact, decreased the public's acceptance of people with mental health disabilities, and in some cases, increased the desire for social distance (Deacon, 2013). Therefore, limiting the way mental health is taught during social work education to this positivist approach may work to promote stigmatizing attitudes among students, and as will be discussed later, decrease the likelihood of hyphen students from disclosing, for fear of shaming or discrimination from peers.

Most participants did recall having taken an elective mental health and social work course; while it was oversight to not ask participants how they felt about the course's elective status, some did suggest the necessity of mandatory mental health



classes in social work education. This may be partially due to the fact that they felt the courses did not cover a sufficient range of topics, or engage their interest:

“...It was like physical health kind-of related things, there was one class on forms like hospital forms, which was, like, interesting, but mental health is so much more than forming someone.”

“I took the one course that was available specifically for mental health, it was taught by a social work professor... I found it very boring, and I remember being it being sort of very technical... I found it really dry and biomedical...”

From both these participants’ experiences, dissonance between what was sought after in terms of mental health education and what was actually available is made clear. While practical skills such as forms and standardized procedure are a necessity in certain social work settings (Burton & van der Brock, 2009), they do not comprise the total of what participants were interested in learning. Research indicates this situation is widespread. For example, Holley et al. (2015) highlight a similar scenario for social workers in the United States: while mental health/Madness stigma is sometimes discussed within social work mental health courses, there is a significant lack of critical discussion of the systemic oppression and political history of this community. Moreover, as reported by Sadow, Ryder, and Webster (2002), simply including content about mental health within health professionals’ education does not seem to reduce stigma they feel towards patients, indicating more needs to be done to develop curriculums that acknowledge this issue.

This may point to a larger problem - that social work education and practice is becoming increasingly depoliticized (Reisch & Jani, 2012). Not knowing the political context in which service users exist and service providers must operate limits social workers' effectiveness. The Canadian Association of Social Workers (CASW) has argued that social workers not only have the breadth and perspective to look beyond illness and treatment issues, but that this is in fact the profession's specific strength and a key part of care (n.d.). Why, then, do social work educational materials for mental health not match up to these clearly stated ideological values? According to Lacasse and Gomory (2003) this is due in part to social work's inability to set itself apart ideologically from psychiatry which has remained dominant in the "ownership" of mental health/Madness practice.

Based on the literature reviewed and participants' perspectives, reliance on a biomedical understanding stifles broader and more complete discussions and learning surrounding mental health and limits practitioners abilities and tools to properly assess clients' needs (Gambrill, 2014). This approach, with its clear distinction between expert and subject (Stromwall, 2002), may also take away client autonomy and perceived power or control over their own bodies (Cook & Jonikas, 2002). Again, for social work students who exist "in the hyphen" (Probst, 2014, p. 25), these unwelcoming conditions may serve to demonstrate the necessity of keeping the mental health disability/Madness part of themselves hidden, for fear of also becoming powerless/voiceless, even if this process is exhausting and limits their ability to live authentically (Lingsom, 2008).

The content within classrooms with respect to mental health disability/Madness is limited at best, but what we learn within the classroom setting is not the only component

that dictates how students – whether they identify with having a mental health disability and/or Madness or not – experience social work education. Personally speaking, a great deal of my own learning about the social work profession came from hearing the stories and opinions of classmates and professors, as well as the classroom culture and general environment experienced.

### **Attitudes of Peers and Faculty**

Overall, participants reported a variety of experiences related to the reactions and support of classmates and professors/field instructors when sharing their mental health experiences. One participant had a great positive experience, explaining: “I had one professor, who was really understanding, they told me after I had my negative placement experience, they told me that everyone has their strengths, and different areas where they work better.” This outcome is a welcome contrast to the lack of expected stigmatizing or discriminatory responses for exposing this part of their identity. Interestingly, this type of gentle support almost equates difficulty in placement due to a mental health disability, as being similar to the many other reasons students may struggle during field education, such as a lack of interest in a particular agency’s work or school-related stress. In this, mental health disability/Madness is not the horrible antecedent to social work practice that students may often assume it to be.

Another participant shared a very difficult field education experience, where their supervisor told them that, because of their mental health symptoms, they had no future as a social worker, and that their only goal should be to get them to finish their placement. While this was several years prior (as the participant was an older student), they

explained it had a profound affect on their identity formation and confidence as a social worker. With inadequate support, students with mental health disabilities and or Madness may be more likely to exit the profession (Moriarty et al., 2009), partially due to the high levels of stigma and lack of confidence about one's ability to practice well (Stromwall, 2002). While anecdotal, it is interesting to note that this student chose to pursue a graduate degree outside of social work, due to multiple reasons, including feeling unwelcome and unfit for continuing practice.

At other times, participants discussed instances where they felt there was almost more of a feeling or underlying current of being unwelcome or an anticipation of being shamed by peers and instructors for their experiences: as one participant explained:

“...nothing overtly externalized to me, again, I would go back to its mostly the internalized. It will come in the form of, like, shame if I don't hand in something on time... Or, I'm listening to my peers all talk about the project they just finished, and I don't share and out myself that I actually have an extension, and that I'm still struggling to get it done... And I don't want them to know that I'm not done because they'll be angry that I have an extension... So yeah, it would be mostly sort of a more quiet, internal, self-censoring experience.”

In this, it seems that this participant has internalized some of the stigma associated with mental health disabilities, in feeling personal shame or inferiority when comparing themselves to their peers. As compared to others, this instance of stigma in the post-secondary environment is more insidious, but still reaffirms the notion of university as disabling from a social constructionist perspective (Hutcheon & Wolbring, 2012). While

this student had been able to negotiate a different date for assignment submission, this (whether consciously or not) made this participant feel inferior to their classmates. While there is limited research regarding the help-seeking behaviours of social work students who experience mental health disability and/or Madness, Adams, Lee, Pritchard, and White (2010) reported that internalized stigma about depression within the medical profession doctors from seeking support. Given that social work's mental health education is also based largely within the biomedical model (Lacasse and Gomory, 2003) a similar barrier may exist for social work students.

Another participant brought up the unique mentoring experience that developed between them and a professor after the student disclosed their mental health experiences:

“That was a big part of my growth, because initially I didn't share with peers and professors. But then, I opened up to one professor and they were a huge mentor to me. So aside from previously having psychopathic [sic] counsellors supporting me, now I had someone who wasn't doing counselling with me, but was a mentor and was someone who could talk to me more like a friend, a mentor – like, it wasn't professionalized, it was okay to talk about broader topics than just seeing a medical professional, if that makes sense.”

From this, it appears that there may be a unique opportunity for mentorship and greater learning through the connection of professors and students who either identify with or are open to discussions of mental health disability and/or Madness. This corresponds with Reid and Poole's (2013) article about Mad students in social work classrooms. One of the authors, Jenna Reid, explained that since she was “identified” as

having a critical understanding of mental health disability and Madness, and had her own personal experiences, she became a “safe person” for students with similar experiences. Speaking from my experience there is a great deal of loneliness and isolation at times that comes with experiencing mental health disabilities anywhere, especially since these challenges are often invisible to others, creating its own set of unique challenges.

### **Invisible Disability: Passing and “Coming Out”**

An interesting, yet unexpected, finding that came up during all the interviews was the challenge that came with negotiating disclosure of what is often an invisible, or not readily apparent disability. Participants explained that it was easier to “stay in the closet” so to speak than come out as being a person with a disability, the frustration of which is captured by Hamilton (1997), as cited by Samuels (2003), who writes: “People with nonvisible disabilities ‘are in a sense forced to pass, and at the same time assumed to be liars’” (p. 242). This quote taps into the real anger and frustration that comes with sometimes being able to pass as normal through complex coping strategies, only to have these be used against students later as implying they are not actually disabled and/or in need of accommodations. In this study, participants echoed the frustration of this arrangement, particularly as it coincides with internal and external stigma. More than anything, this can be understood as another instance of the university environment as being inherently disabling (Hutcheon & Wolbring, 2012), where students are colloquially speaking – damned if they do, and damned if they don’t.

Despite the issues passing may bring up, this process of negotiating, and strategizing is, for participants, an act of survival. As revealed by one participant who explained why they chose not to reveal mental health information about themselves:

“...Probably because I just really wanted to do well, and I always wanted people to have the best impression of me... probably because I thought it was a weakness, so I didn’t want people to see that side of me.”

As another participant explained that there is often a great deal of forethought and planning required in order to maintain professional status and credibility; in this particular instance, they received advice from the placement coordinator about if and how to disclose:

“They sort of encouraged me to strategically withhold it – if you want to share that in person, once you have a sense of them, which I think was sound advice. I withheld it from the application – I didn’t include that self-identifying information which I was very excited to include because I was growing into it and owning it. So I remember at the time, I was a bit taken aback...”

This is a different example from others presented in the analysis, in that this student is essentially discussing an instance of wanting to reclaim previously hurtful mental health disability labels ascribed to them, which is line with Mad studies principles (MacDougall, 2013), but being advised against doing so. It should be noted, however, that the placement coordinator’s advice, however, did not come from a place of malice, rather, they were doing their best to ensure their student was able to secure an appropriate

placement. The fact that they chose this strategy, then, again speaks to the broader social work culture surrounding mental health disability.

Moreover, as another participant explained, this type of strategic identity formation continues within the workplace as well. In response to a question about disclosing their mental health status during the employment seeking and hiring process, this participant explained:

“No - you would never get the job... I would never say anything. And also, you don't really know who you're disclosing to... Also you're disclosing to someone from whom you may or not get the job, and you don't sign a confidentiality agreement, right? And social work is a small community, right? So if you say something to one person, two or three years later down the road...”

The fear and challenges associated with disclosing disability in the workplace are well documented with the literature, particularly the perceived risk of individuals that disclosure will result in not being hired, or losing a job (Wilton, 2006; von Schrader, Malzer, & Bruyere, 2014). According to Brohan et al. (2012), the concern of being stigmatized as a result of disclosure specifically involves several key fears, including not being hired, unfair treatment in the workplace, or being unprotected by existing legislation. These concerns may be further complicated by other aspects of individuals' identities, coming together to influence how they are perceived by others, including peers, professors, and future employers.



### **The Intersection of Mental Health Identity**

During their interviews, several participants also disclosed other oppressed aspects of their identities that, similar to a mental health disability, are not readily apparent – adding to the challenges of “passing”. Within the literature, this concept correlates well in discussions of sexuality, which Samuels (2003) suggests holds many parallels to an invisible disability, in that individuals must choose if and how to express this part of their identity and are often privy to conversations (and perhaps even discriminatory remarks) about their experiences that may not have been said if they were “out”. Moreover, like any other aspect of identity, mental health disabilities/Madness do not exist within a vacuum, and the way these issues interact with traits such as sexuality, race, appearance, age, and others can contribute to a variety of challenges.

For example, one participant identified as Indigenous, and discussed the unique challenge of navigating multiple oppressed identities, particularly given the fact that neither their mental health status nor their racial identity was readily apparent to others:

“You know, in course work you learn about First Nations people, and it’s almost just statistics you learn about. And I’m like, ‘Oh well I guess I’m just fitting into the statistics of who I’m supposed to be’, rather than separating things from yourself and recognizing that they’re all pieces of your identity, that doesn’t need to be related, and it’s not all that you are.”

These ideas are echoed by Gray (2016) who challenges the way mental health issues within the Indigenous community are taken up, where individual responsibility and deficits are emphasized, while erasing the real impact of previous and continued colonial

violence. Individualized, deficit-based notions of disability do not provide a space to consider the historical and current-day violence against First Nations, leading to erasure of very impactful experiences. This participant's comment also arguably highlighted a key consequence of limited or one-sided teaching about any group's experiences within social work education: when only the dominant, discriminatory perspective is shared, this can, for members of that group, lead to increased isolation, as well as fear of fulfilling negative stereotypes.

Another participant similarly shared their experience of being fearful of falling into an established stereotype that draws upon multiple aspects of her identity:

“In the social work program, I remember not wanting to do things because I was fat... and it really affects your identity. I remember at one time I was really paranoid about being perceived as crazy, and I was really worried about being perceived as that fat, brazen... you know how fat women are portrayed? And that the idea that you're so crass, and that you're the aggressive fat lady.”

In this, there is again a fear of exposing oneself and being put into a “box” with a specific prescribed set of often-undesirable traits and identities, through the layering of oppression associated with multiple identities. In addition, the stigma that comes from experiencing mental health disability and/or Madness is also influenced by other factors, such as racial identity (Deepa, Feinglass, & Corrigan, 2007) and sexual orientation (Bostwick, Boyd, Hughes, & West, 2014).

Another participant reported that their experience of oppression stemming from

their mental health disability was actually in opposition to their overall experience of relative privilege, creating its own set of complications:

“As a cisgender, white male, English-speaking, and typically perceived as heterosexual, I don’t face many barriers, or I don’t perceive that I face many identity-based barriers; mental health would be the exclusive one...I find my vulnerabilities to oppression are all very easy to hide, so I don’t experience direct, blatant oppression... I kind of fly under the radar of oppressive actions.”

In this example, the participant is again benefitting from being able to pass, which is facilitated by their being able to depend on the privilege that comes from other aspects of their identity (e.g. race, gender), which help them to navigate the world more easily. However, this type of arrangement is not without its own kind of distress, in that if this participant did choose to be open about their mental health disability/Madness, they would still be vulnerable to oppression and discrimination. Therefore, this privilege only goes as far as their ability to play their hand, so to speak, and strategically hide a major component of who they are.

### **Feeling “Unworthy” of Support**

As has been addressed, related to the notion of having an invisible disability is the fear and uncertainty that comes with having to choose to engage or not engage with the “coming out” process (Matthews, 2009). This may be important to some people in order to live their authentic lives, or to access necessary supports. This becomes especially difficult when disclosure becomes a necessity for receiving academic accommodations, either formally or informally. None of the four participants interviewed during this study

sought formal academic accommodations during their social work education. When asked to explain why, there were a couple of explanations offered, including not being open with oneself about their mental health status, or being unclear of how the process actually works. However, the most common theme that came up was the feeling of unworthiness and not being deserving of formal academic accommodations. As one participant explained:

“In my mind it was not okay to ask for accommodations because, again, not deserving it because I should be able to do this. There’s definitely a huge self talk of, like, I should be able to do this without getting support... I felt it [formal accommodations] was cheating... which I know is wrong, but that’s how I felt.”

This participant is not alone in wrestling with the idea of accommodations as being a form of cheating or unfair advantage, as it is a currently a dilemma across academic institutions. For example, Rowe (2006) argues that if providing students with academic accommodations (as mandated by law), goes too far, it will hurt other students by making the playing field unlevelled, and putting students without appropriate skill levels into practice. This external negativity towards academic accommodations may also be compounded by internalized stigma held by social work students who identify with having a mental health disability and/or Madness. For example, Eisenberg, Downs, Golberstein, and Zivin (2009) reported that personal stigma (which includes self-stigma) was negatively associated with help seeking behaviour, forming a barrier to these students accessing support because of their own attitudes.

Another relevant factor is possibly at play here: Siebert and Siebert (2007) explain that the identity formation that social workers (and other helping professionals) go through during their formal education plays a major role in their ability to seek help and support when they need it. Not only is the role of helper paramount in workers' lives, an idealized and unrealistic version of this role is often placed upon workers by clients and, as well, as friends and family. The idealized role of helper comes with the implication/assumption that you do not require help (Siebert & Siebert, 2007). In trying to negotiate being a service user and a social worker in an educational setting that does not often acknowledge that this exists. These students may in fact feel added pressure to conform to the ideal helper role, as a means of asserting their belonging within the social work profession.

As another participant summarized, there is a sense of combating feelings of inadequacy and being ill-prepared when explaining why they chose not to pursue academic accommodations: "...I remember thinking, well, if I can't cut it in school, how can I cut it in the field?" In this, accommodations are conceptualized as being merit-based, as opposed to a being an entitlement, a right enshrined in legislation, and exposes the larger trade-off that occurs for social work students with mental health disabilities. While their issues may not be readily apparent – and means that they will be more likely to be treated "normally" – this also means that the validity of their claims of disability may not be taken as seriously, and others may not truly understand or accept their needs for accommodation and support or the extent of their conditions (Mullins & Preyde, 2013).

This type of thinking points to larger issue of viewing academic accommodations as merit-based or entitlements, rather than tools that promotes equity, as opposed to equality, within post-secondary education. There are concerns, for example, that as more students access academic accommodations, that this is a slippery slope that undermines the level of academic excellence required of a university education (Stevenson, 2010). Attitudes of professors and other faculty like this only serve to increase barriers between students and appropriate accommodations (Mullins & Preyde, 2013). Another point is the burden of proof on individuals who experience mental health disabilities, in that they often do not appear to be struggling (perhaps due to the limited understandings of what mental health disabilities actually look like), and therefore may just be trying to game the system (Olney & Brockelman, 2003). This points to the idea that professors require more training surrounding academic accommodations, including how they benefit classes overall, and that they cannot be blanket responses, but tailored to students' specific experiences (Mandelaro, 2016).

Overall, the negotiation of feeling unworthy then may come from the assumption surrounding academic accommodations as cheating or being unfair advantage. This back-and-forth, then, only provides another setting in which social work students with mental health disabilities and/or Madness negotiate dichotomies, and the uncertainty that comes from existing “in the hyphen” (Probst, 2014, p. 25), while simultaneously managing the challenges faced during all social work students in learning to move into the new identity as practitioner (Shlomo, Levy, & Itzhaky, 2012).

### **Professional and Personal Identities Collide**

Probst (2014) interviewed therapists who were also seeking therapy, and explained that the “client-clinician hyphen is a delicate, ever-changing interface, as fraught with potential danger to patient and/or therapist as it was with potential benefit” (p. 31). A similar thread of ever-changing ambivalence, uncertainty, strength, and weakness flowed through the interviews in this project. When asked about the words they would use to describe themselves (between social worker, survivor, or other), most participants did not have a straightforward answer, explaining that they were still trying to sort it all out. This can cause a great deal of distress, even when moving beyond the classroom and into the workplace, where the distress and dissonance that comes with hiding a part of one’s identity may even be worse than the distress of coming out.

As one participant explained:

“I think often times we feel like we need to be the helpers, and it needs to be all on us, and kind of ignore things and put them on the back burner, and then there’s a lot of burnout, especially if you already have limitations... that can be monumentally overwhelming.”

This sentiment is echoed by Reid and Poole (2013), explaining that the limited way mental health is discussed and taught within social work education settings promotes an “us versus them” mentality, that leaves students in both worlds unsure of where to stand.

An additional layer of challenge comes from the fact that the decision to become a social worker is often intertwined with one’s individual experiences, including mental health. As one participant explained:

“...I eventually got my calling, it came to me that this is my work. This is... I have a lot to give to people who similarly struggle... So I looked up a master’s in social work and it was like *oh my god*, it was kind of just magical, that I looked it up for the purpose of psychotherapy ... This is who I am, this is what I’m about – the whole big picture, the social justice, the environment, the people...”

This is such an important example of the fact that people perhaps coming into the profession for personal reasons does not necessarily take away from the passion these practitioners may feel, or their ability to perform in a meaningful, productive way (Solomon, 2004). “There’s also the stigma that if you get into social work because of your own issues, you’re just bringing up your own shit [sic], and then you’re not a good practitioner.” Overall, while these students may have a great deal to offer, they may choose not to share these aspects of themselves for fear of judgement, as well as not having role models or an educational backing on the most effective way of sharing this part of themselves. This is in spite of the fact that these individuals can offer a unique perspective, and perhaps more comprehensive support for clients experiencing similar challenges (Frese & Walker Davis, 1997).



## Discussion

Interviewing participants who identified as experiencing mental health disability and/or Madness provided invaluable information about their learning and professionalization within social work education. It also made clear some of the overarching ideas and experiences that may, upon future investigation, reveal themselves to not only be characteristic of this participant group, but the community at large. The first of these is the lack of incorporation of alternative approaches to mental health disability and Madness (e.g. Mad studies) within social work education (Holly et al., 2015). This means that many people who identify as having these types of experiences may not have the chance to consider a politicized understanding of mental health nor be introduced to the type of language that would lead them to self-identifying as Mad. The dearth of this alternative content within social work education can be attributed to the biomedical and psychiatric focus of social work education (Morley & Macfarlane, 2010). By conceptualizing mental health disabilities as individualized deficits, and social work practitioners as experts in providing care, stigmatizing ideas about mental health disability are perpetuated, arguably becoming engrained within the culture of the institution and the profession.

The challenge in addressing this potentially stigmatizing culture surrounding mental health is that it is often an unintentional expression of structural discrimination built within institutions, such as universities (Corrigan et al., 2004). It is often expressed in subtle and insidious ways, such as the attitudes and behaviours of peers and faculty towards participants and mental health disability and Madness in general. This can be

expressed in several ways, including microaggressions (Gonzales, Davidoff, Nadal, Yanos, 2014) - borrowed from critical race theory - and internalized ableism. Given the current cultural climate and the fact that mental health disability is often invisible, these students are often required to negotiate and manage how they present themselves to others. This process is only further complicated by the fact that mental health status is only one component of the intersecting and overlapping facets of identity that individuals carry, and as such, this experience of stigma is influenced by other factors, including race, sexuality, and socioeconomic status.

Overall, these factors highlight the unique challenge that comes from being both and neither. While the presence of individuals who experience mental health disability and/or Madness within social work education is rarely discussed or critically examined, the findings of this study demonstrate just how much this struggle is based in how social work education is structured. While small in nature, this project has taken a step forward in expanding the conversation about social work students who experience mental health disability and/or Madness. Also addressing the ethical issues encountered in this project, while not the focus of this study, this outcome adds to the growing base of literature (e.g. Reid & Poole, 2013; Schneider, 2012) that asserts that the mental health disability and Mad communities are able to meaningfully collaborate on research projects about them.

### **A Common Thread: Stigma, Self-Stigma, and Disclosure**

These themes, while all speaking to different components of participants' experience, continually return to the idea of negotiating disclosure and stigma, in multiple forms. As Corrigan and Rao (2012) explain, the way stigmatizing ideas are publicly

experienced by individuals who experience mental health disability and/or Madness influence their own ideas about themselves and their self-worth. This may include the ways mental health is discussed and taught within social work education, and the overall culture of mental health at universities. Individuals then take in these ideas as informing their own self-stigma, which can contribute to multiple reactions, including experiences of shame and/or fear related to disclosure. Disclosure itself is also a complex process, in that it is not an all-or-nothing proposition – participants strategically chose to share some information to some people, and not others, depending on multiple situational factors. These included perceived safety of colleagues and professors, personal ideas about mental health disability and Madness, and the accessibility of the accommodations process.

As Pilling (2013) discusses, these challenges come up again as students enter the workforce, where they again face uncertainty around disclosure and fear of stigma, particularly since individuals are often measured against able-bodied work standards. The concept of being able-bodied is in contrast with being disabled, and it can be seen that a biomedical understanding of these phenomenon further perpetuate ideas of being sick *or* well, rather than a spectrum of ability. It could be further argued then that, given the professional nature of social work education, this type of fear and uncertainty may exist within into the classroom and field practicum settings as well.

Overall, this project adds to the discourse surrounding mental health stigma and disclosure, with a novel focus on social work education. By focusing on the experience of the “therapatient” (p.887), this project also builds on recommendations of Goldberg and colleagues (2015), by highlighting the often hidden experiences of individuals who are

both and neither as a starting point for discussion. Given the richness of findings about the interplay of stigma and disclosure for this community, future projects may do well to continue with this approach, which also allows for fuller inclusion of this community.

### **Limitations**

While this project provided a great deal of insight into topics that are only recently becoming more commonly discussed, there are also several constraints that limit the applicability of these findings. The first of these refers to the scale and reach of the project, which was significantly limited by both time and budget constraints, as is common for a one-year master's thesis project. A major result of this was the limited number of interviews that could be included as part of this project. Similarly, recruitment for this project was limited only to alumni of McMaster University's School of Social Work, who had been registered in the program between 2011 and 2015 inclusive. While some participants did mention attending other schools of social throughout their education, the majority of the interview questions focused on their experience at McMaster, and as such, their experiences may not be transferrable or applicable to social work education in Canada more broadly.

Thirdly, financial and time-related constraints also created challenges to conducting this research in a way that better aligns with the tenets of the theoretical frameworks guiding this study. For example, a key tenet of Mad Studies is the notion of "nothing about us without us" (Ochocka, Janzen, & Nelson, 2002) implying that any research about the community should involve individuals with lived experience at each step – from study conception, to data collection, to analysis and sharing findings. Taking

this to heart, I was in charge of all aspects of this research project, along with guidance from my supervisor, who also operates from a similar critical lens. However, while I am someone who identifies with the participation population, I am only one voice, and this is not nearly enough to really *do* the kind of participatory action research that is deemed essential within Mad Studies. Moreover, another major component of this type of research is a focus beyond the academic – where findings are actually shared and applied in a way that promotes social change. Therefore, it is important to look at next steps and future directions to continue and promote the ideas introduced here.

## **Conclusion**

As a conclusion to the each of the interviews for this study, I had planned to ask participants about the changes they would like to see in social work education with regards to mental health disability/Madness and ways they would begin to implement these improvements. While this is quite a grand question, and an important one at that, it almost turned out to be unnecessary, as each participant had already brought forward their own suggestions and ideas throughout our discussions, sharing their own unique insights that can only come through lived experience. However, these recommendations often came as a way of resolving or rectifying unsettling situations from their own experiences, with intention of changing the status quo for future students and practitioners. Therefore, as a way of trying to collect and reflect upon what has been said, I plan to conclude this project by first reiterating the positive and some of the harder experiences participants shared, alongside recommendations for social work education as guided by participant suggestions and the literature. Following these recommendations may be a first step in addressing the research goals of deciding what works and what changes are necessary – ultimately rectifying the experiences created by living “in the hyphen” (Probst, 2014, p. 25). These recommendations are best captured within three overall implications for social worked education, covering formal learning, accommodations, and the overall mental health culture within post-secondary social work settings.

### **Implications for Social Work Education**

**Required learning.** A common theme throughout participants’ interviews was the existence of major gaps in how mental health was discussed formally (e.g. course

readings, presentations) and informally (e.g. class discussions) within social work education. Their recommendations for addressing this gap are supported in the literature. Participants suggested the introduction of a required social work course dedicated to mental health, particularly one that moves beyond the traditional clinical discussions that are currently commonplace (Lacasse and Gomory, 2003). This should also include the introduction of different types of assignments that move beyond traditional formats, such as participating in social justice campaigns, or interviewing individuals within the community who have lived experience (Meyers, 2007). Moreover, it is equally important to introduce more political discussions of mental health disabilities/Madness, including the oppression that these communities face, as well as the history of protest and counter-culture surrounding mental health, including the psychiatric survivor movement (Holley et al., 2015). Including this will also help to expand the way in which mental health disabilities/Madness are discussed, and will help move it to being a topic discussed in a similar way to other facets of identity, such as race, socioeconomic status, and sexuality. Finally, it is important that social work professors and other faculty are also operating from a complete and critical foundational understanding of mental health disabilities/Madness.

**Easier access to accommodations.** When discussing access to academic accommodations, participants assert that there are multiple barriers that need to be tackled. The first of these involves more clarification about *how* to actually go about the steps required to obtain accommodations, which are often hard to find, particularly when students are unsure of who they can trust with sharing their mental health experiences.

Similarly, participants questioned the necessity of having to present a medical diagnosis from a physician in order to have access to formal accommodations. This only serves to prioritize the biomedical conceptualization of mental health, and also creates a culture of distrust and having to justify the way individuals exist in the world. These barriers mean that students often turn to professors directly to arrange for alternative due dates or assignment modifications (Salzer, Wick, & Rogers, 2008), a common solution for participants as well. While there is nothing wrong with being able to negotiate with professors, directly, there is also arguably a great deal of potential in having student accessibility services' resources truly support students who experience mental health disabilities/Madness. Moreover, making these changes should add to changes in mental health culture within social work education, as well as post-secondary education on a larger scale.

**Create spaces for peer support and mentorship.** An exciting, and somewhat unexpected finding was the positive experience that came from being able to share one's mental health disability/Madness. A particular area for this, as identified by participants, is having faculty and older students that are available as mentors; a designation that often begins simply with these potential mentors being out or open about their mental health status. Within professional fields, having a mentor is important and provides a variety of benefits for mentees (Lee & del Carmen Montiel, 2011) and mentors (Eby, Durley, Evans, & Ragins, 2006). It's also important that mentees are able to connect to commonalities with their mentors, particularly in instances where such traits are not dominant or as frequently discussed. As previously mentioned, it can be an incredibly isolating



experience to feel that no one else is going through something similar, and it also creates a great deal of uncertainty when navigating new challenges, such as the transition from student to professional. Engaging with someone who has already made that journey not only provides the opportunity to learn strategies and ways of handling challenging situations, it can also instil hope and normalizes students' own experiences.

### **Future Research Directions**

This is an exciting time for expanding the discussion surrounding mental health and ability within social work education, as well as the development of the whole person as a social worker, blurring the divide between practitioners and service users, between us and them. However, this project – while adding to these conversations – is only a very small step on a continuing path, with many future directions and research questions to still consider. For example, a topic brought up by project participants is if and how to engage in self-disclosure when working with clients in practice settings. This is already a blurry and complex issue within clinical work with clients in general (Peterson, 2002), let alone situations where disclosure involves mental health disability/Madness. Moreover, as part of changing the culture surrounding mental health disability/Madness within academia, another future direction stemming from this project involves better educating research ethics boards about mental health so that future research projects can more easily further discussions, work to reduce stigmatizing policies, and better include people with lived mental health experience.

Because of its unique, multi-layer perspective, social work is in a powerful position to change the dominant conceptualization and public understanding of mental

health disabilities/Madness, and this begins while social workers are still students (Reid and Poole, 2013). Overall, while social work students who identify as experiencing mental health disabilities and/or Madness may experience many challenges, they can often be resilient and resourceful, and have plans to bring their unique experience to their work with clients in the future (refs). Based on the learning from this research project, what is needed most is a cultural shift in how mental health disabilities/Madness is understood, discussed, and taught. Keeping things as they are will only continue to perpetuate a status quo that ignores an important aspect of practice and social work practitioners' identity. Not only does this create real consequences for individuals whose lives remain as 'both and neither', it also limits social work's ability as a whole to truly advocate for and ally with mental health disability and Mad communities. While this transition will most certainly take time, I argue it is a necessary one so that students who exist in the hyphen are able to have a place of their own, so that they can flourish and share their unique insights and skills with clients and colleagues alike, expanding the knowledge and skills of fellow practitioners as they do so.

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## Appendix A: General Email Recruitment Letter

### *Email Recruitment Script*

#### *Sent on Behalf of the Researcher by the Holder of the Participants' Contact Information*

**Amanda Suleiman, B.Sc., B.S.W.**

Masters Candidate in Social Work

#### **Study Title:**

Both and Neither: Navigating the Experiences of Recent Social Work Alumni who Experience Mental Health Issues and/or Madness

---

#### **Sample E-mail Subject Line:**

McMaster study about the experiences of former social work students who experience(d) mental health issues/madness

Dear McMaster Social Work Alumni,

Amanda Suleiman, who is currently a student in the McMaster MSW program, has contacted me to ask that I let former social work students know about a study she is doing about the experiences of social work students who experience mental health issues and/or identify as mad. Amanda also identifies as a student who experiences mental health issues, and as such is both professionally and personally passionate about this research topic.

If you are interested in getting more information about taking part in Amanda's study please read the brief description below and or **CONTACT AMANDA SULIEMAN DIRECTLY** by using her McMaster email address: [suleia1@mcmaster.ca](mailto:suleia1@mcmaster.ca). Amanda will not tell me or anyone else at the McMaster School of Social Work who chose to participate or not. Also, taking part or not taking part in this study will also not affect your status, relationships, or services you receive at the McMaster School of Social Work or McMaster University.

This research is part of her graduate thesis, necessary for her completion of the MSW program here at McMaster. The following is a brief description of her study:

Amanda Suleiman is inviting you to participate in a one-time, hour-long in-person interview with her that will take place at a convenient time and place for you in the community, including evenings and weekends if necessary. She will work out these details with you directly. She hopes to learn more about your experiences during your social work education, placement, and your beginning years in the field while also experiencing mental health issues. Ms. Suleiman has explained that you can stop being a part of the study at any time during the interview, or choose not to answer certain questions. She has also asked us to attach a copy of her information letter to this email. That letter gives you full details about her study.

In addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat  
Telephone: (905) 525-9140 ext. 23142  
Gilmour Hall – Room 305 (ROADS)  
E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)

Sincerely,

Darlene Savoy  
Director's/Graduate Administrative Assistant  
School of Social Work – McMaster University



## Appendix B: Letter of Information/Consent Form

### LETTER OF INFORMATION / CONSENT

*Both and Neither: Navigating the Experiences of Recent Social Work Alumni who Experience Mental Health Issues and/or Madness*

**Principal Investigator:**

Dr. Ann Fudge-Schormans  
School of Social Work  
Faculty of Social Sciences  
McMaster University  
Hamilton, Ontario, Canada  
**(905) 525-9140 ext. 23790**

E-mail: fschorm@mcmaster.ca

**Student Investigator:**

Amanda Suleiman, B.Sc., B.S.W.  
School of Social Work  
Faculty of Social Sciences  
McMaster University  
Hamilton, Ontario, Canada

E-mail: suleia1@mcmaster.ca

**What is the purpose of this study?**

You are invited to take part in this study about the experiences of recent social work students who experience mental health issues and/or identify as mad. I am interested in learning more about how the current social work education program, curriculum, and structure influences these experiences. I am also hoping to learn more about what is working, and what changes (if any) you think may be needed. I am doing this research as part of my thesis for my master of social work degree, with the supervision of Dr. Fudge-Schormans at McMaster University.

**What will happen during the study?**

The study involves a one-on-one interview with myself (Amanda Suleiman) that should take approximately 45 minutes to one hour to complete. The interview will take place in a secluded location that is convenient for you within the community, such as a private room on McMaster's campus, or at a public library. To keep track of what has been said, I will be taking some hand-written notes, as well as audio-recording the interview, with your permission.

I will be asking you some questions about your experiences during your time as a social work student while experiencing mental health issues, including:

- (1) What was your experience like as a student with mental health issues while completing your social work education?
- (2) What challenges have you faced related to your mental health and education/profession?
- (3) Have you tried to reach out for support or accommodations? What was that process like for you?

I will also ask you for some demographic/background information, including your age and which years you were enrolled as a social work student.

To begin, I will introduce myself and provide a brief explanation of my research, including going through this Letter of Information/Consent Form. Next, you will have an opportunity to review the complete list of questions prior to beginning the interview, and make note of any questions you do not feel comfortable answering. I will also confirm that you are comfortable with me taking written notes and audio-recording the interview. I may ask you specific follow-up questions based on what you share which you can choose whether or not to answer. We can also take a break whenever needed.

**Are there any risks to doing this study?**

The risks involved in participating in this study are minimal. Some of the topics discussed may be triggering, or may make you feel uncomfortable. The interview itself will also last between 45 minutes and one hour, which may be draining. Breaks can be taken as needed to alleviate this. You do not need to answer any questions that you do not want to answer or that make you feel uncomfortable. You are welcome to stop the interview at anytime with no consequences. I describe below the steps I am taking to protect your privacy.

**Are there any benefits to doing this study?**

The research will not benefit you directly. I hope to learn more about the experiences of social work students with mental health issues to contribute to an important discussion about madness and social work. I hope that results of this research study can be used to advocate for positive changes, including greater acknowledgement and acceptance, as well as improved experiences for future students.

**Reimbursement**

You will receive a \$10 Tim Horton's gift card as a token of appreciation for your time and contribution to this project.

**Who will know what I said or did in the study?**

You are participating in this study confidentially and every effort will be made to protect your privacy. I will not use your name or any information that would allow you to be identified. No one but my supervisor, Dr. Fudge-Schormans, and I will know whether you were in the study unless you choose to tell them. However, we are sometimes identifiable through the stories we tell, and McMaster's social work community is not very large – please keep this in mind in deciding what to tell me. Pseudonyms may be used as necessary, and any key points that include identifying information can be edited to protect privacy.

The information you provide on this form will be kept in a locked cabinet where only I will have access to it. Interview recordings and other electronic data will be kept on a computer, protected by password. Once the study is complete, an archive of the data, without identifying information, will be maintained for seven years.

**Legally Required Disclosure:**

Although I will protect your privacy as outlined above, if the law or duty requires it, I will have to reveal certain personal information in the following circumstances:

- If I am concerned that you are at immediate risk of harming yourself or someone else, I will be required to tell someone and take steps to minimize this risk
- If you tell me that there is a child under the age of 16 who is experiencing abuse and/or neglect, I have a duty to report this to the local Children's Aid Society
- If you tell me that you were sexually abused by a helping professional (e.g. doctor, psychologist), and you tell me their name, I have a duty to report this information to their professional college
- If for some reason, my records are subpoenaed by a court of law, I will be required to comply and provide this information

If one or more of these situations does arise, however, I will do my best to let you know before any action is taken.

**Where will my data be kept?**

After your interview, the audio file will be transcribed into a Word document, and the audio file will be destroyed. Your demographic survey and interview transcript will be kept in a confidential, secure location for a period of three years after the end of the study, at which point it will also be destroyed.

**What if I change my mind about being in the study?**

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can withdraw from or stop the interview at anytime for whatever reason, even after signing the consent form or partway through the interview. You will have up until approximately July 31, 2016 to withdraw your participation, at which point I expect to begin completing and submitting my graduate thesis.

If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not affect your continuing relationship to McMaster University's School of Social Work or alumni network.

**How do I find out what was learned in this study?**

I expect to have this study completed by approximately August 2016. If you would like a brief summary of the results, please let me know how you would like it sent to you below. It should be sent out in Fall 2016.

**What will the findings from this research study be used for?**

The information collected during this research project will be used to write my masters thesis. If there is an opportunity, I may also present this research and any findings at an academic conference, or publish any findings in an academic journal. If this does occur, your confidentiality would be protected and no identifying information would be released. Moreover, information collected during this research project may be used as a foundation for a future dissertation project if I choose to pursue a doctorate of social work in the future. Again, if this does occur, your confidentiality will continue to be of utmost importance,

**Questions about the Study:**

If you have questions or need more information about the study itself, please contact me at:

<p style="text-align: center;"><i>Amanda Suleiman</i> <i>suleia1@mcmaster.ca</i></p>
--

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat  
Telephone: (905) 525-9140 ext. 23142  
C/o Research Office for Administrative Development and Support  
E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)

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**CONSENT**

- I have read the information presented in the information letter about a study being conducted by Amanda Suleiman, of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time or up until approximately July 2016.
- I have been given a copy of this form.
- I agree to participate in the study.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Participant (Printed) \_\_\_\_\_

1. I agree that written notes can be taken during this interview.

Yes

No

2. I agree that the interview can be audio recorded.

Yes

No

3.  Yes, I would like to receive a summary of the study's results.

Please send them to me at this email address \_\_\_\_\_

Or to this mailing address \_\_\_\_\_

\_\_\_\_\_

No, I do not want to receive a summary of the study's results.

4. I agree that the researcher may contact me again at a later date to clarify or confirm information.

Yes

No

## **Appendix C: Interview Guide**

**NOTE:** For consistency in this guide, I have chosen to use the specific language of “mental health disability” to refer to the diversity of experiences participants may hold. During interviews, and writing about these interviews afterwards, I will honour and take up the chosen language of each participant taken from the demographics form (Appendix 3).

### **Additional information about these interview questions:**

- This guide gives you an idea what I would like to learn about your experiences during your social work education as a person who experiences mental health issues
  - Interviews will be one-to-one and will be open-ended (not just “yes or no” answers). Because of this, the exact wording may change a little.
    - Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: “*So, you are saying that...?*), to get more information (“*Please tell me more?*”), or to learn what you think or feel about something (“*Why do you think that is...?*”).
    - I may also ask you additional questions that are not included in this guide to learn more about specific experiences and ideas you share. As with all other questions, it is your choice whether or not you choose to answer these.
  - You will have an opportunity to review these questions prior to starting the interview, and you can choose not to answer any questions you would prefer not to.
  - Please note that while your identity will be kept anonymous, we are often potentially identifiable from the stories we tell. Therefore, please be mindful in the stories you share.
- 

**1) Can you tell me a little bit about yourself? What do you think drew you to participating in this research study?**

**2) Why do you think you chose to pursue social work as a career choice?**

- Do you think your experiences with mental health disability influenced this choice at all?
- If so, how?

*Okay, now I would like to begin discussing your experiences during your social work education in the classroom...*

**3) Did you choose to share information about your mental health disability with any of your peers?**

- If so, what was that experience like for you?
- Did it change your relationship with that person? If so, how?
- Looking back, how do you feel now about having shared that information?
- Did this experience change the way you did things in future instances?

**4) Did you choose to share information about your mental health disability with any of your professors?**

- If so, what was that experience like for you?

- Did it change your relationship with that person? If so, how?
  - Looking back, how do you feel now about having shared that information?
  - Did this experience change the way you did things in future instances?
- 5) Was mental health formally included as part of the curriculum/readings/topics during your social work classes?**
- What type of language was used? How did you feel about it?
  - Do you feel that anything was left out? If so, what else would you like to have seen?
  - Was the mental health content what you had expected? Why or why not?
- 6) Was mental health brought up informally during classroom discussions?**
- What type of language was used? How did you feel about it?
- 7) What kind of ideas do you think your non-disabled classmates would come away with based on how mental health was brought up formally and informally during your social work classes?**
- Is there any thing else that...
- 8) Have you tried accessing supports related to your mental health? If so, what was that process like for you?**
- Was this a formal process (e.g. through Student Accessibility Services on campus)?
    - If so, can you tell me what that was like for you?
  - Did you seek supports/accommodations informally (e.g. speaking to professors one-on-one)?
    - If so, can you tell what that was like for you?
- 9) If you did seek supports related to your mental health disability (either formally or informally), were you required to disclose specific details (e.g. diagnoses) in order to justify requested supports?**
- If so, how did you feel about this?
- 10) Some other research on this topic<sup>1</sup> has suggested that social work students with mental health disabilities may occupy both a service user and service provider role, which may lead to particular challenges within social work classes. Has this ever been an issue for you?**
- If so, can you tell me more about what that was like for you?
  - Do you think this type of experience impacted your confidence in terms of becoming a practitioner?
  - Do you think class facilitators consider/acknowledge that students may also be potential service users?

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<sup>1</sup> Reid, J., & Poole, J. (2013). Mad students in the social work classroom? Notes from the beginnings of an inquiry. *Journal of Progressive Human Studies*, 24(3), 209-222.

**11) In addition to your mental health disability, there are many other aspects that make up your identity and who you are. Did other components of your identity affect the experiences you've talked about so far?**

- What has that been like for you?

*Now I'd like to ask you a few questions about your time and experience during field placement...*

**12) What was the preparation and application process for your field placement like for you?**

- Did you take your mental health disability into account when deciding what places to apply for placement?
- Did your mental health disability affect your ability to find a placement?
- Were you open about your mental health disability to the placement coordinator? Within your applications?

**13) What were your placement experiences like for you?**

- Where did you complete your social work placements? (either name of agency or type of organization)
- Was mental health discussed within these settings? (e.g. both at the actual agency, and during seminars, readings, etc.)

**14) Did you share your personal mental health experiences in these settings?**

- What was that process like for you?
- Did you regret sharing this information? Did it affect the way you discussed your own mental health in the future?
- Do you think it affected how your supervisors, peers, and other members of the agency acted towards you?

*For this part of the interview, I would like to talk about any challenging experiences that have come up based on your mental health disability...*

**15) Have there been instances where you have experienced discrimination or stigma as a result of your mental health status?**

- Was the situation eventually resolved? If so, how? If not, why do you think that is?
- Did these types of experiences affect how you saw yourself as a social worker?

*We have done a lot of reflection about your past educational experiences, I would now like to ask a few questions about how all these things have influenced your professional identity and work...*

**16) Based on your experiences during your social work education, what has entering the workforce been like for you?**

- Do you see any connection between your experiences in university and beginning work as a social worker?

- How did you go about looking for jobs?
- Did your mental health status have an impact on your job application process? Did it affect the types of agencies you chose/deliberately chose not to apply to?

**17) What words would you describe yourself as related to employment/professional life?**

**18) Are you currently working in a social work position right now?**

- a. If you are currently working, are you open about your mental health status?
  - If so, how did that process go for you? Are you comfortable with the choice you made?
  - If not, was this a deliberate choice? What factors do you think encourage your choice to not share this information?
- b. If not currently working, do you think your mental health status is related to this decision?

**19) Do you see yourself as a social worker? Do you see yourself as a service user? Survivor? Why?**

- How important do you think language is to you when understanding your own professional and personal identity?

*Before we wrap up, I would like to ask you a few more questions that are broader in scope...*

**20) How do you think social work education compares to university in general in its understanding and discussion of mental health?**

- Do you think social work education has a responsibility at university-level when it comes to challenging mental health stigma?

**21) What changes (if any) would you like to see in terms of how mental health is taught and discussed within social work education?**

- What are some first steps that can be taken to reach these goals?

**22) Is there anything else that you would like to share? Is there anything else that I have forgotten that you think is important to include?**

Thank you very much for your time and valued input, ideas, and experiences. It is sincerely appreciated.



## **Appendix D: List of Support Services for Participants**

### ***List of Support Services for Participants***

#### Personal Support

##### **COAST (Crisis Outreach and Support Team) Hamilton**

24/7 Support via telephone  
905-972-8338

##### **Canadian Mental Health Association – Hamilton**

905- 521-0090  
<http://www.cmhahamilton.ca/>  
Provides individual support and groups; branches located across Canada and can be found online

##### **Assaulted Women’s Helpline**

1-866-863-0511  
<http://www.awhl.org/>

##### **Ontario Mental Health Helpline**

1-866-531-2600  
<http://www.mentalhealthhelpline.ca/>  
Can also be reached via online chat at website; provides information about various mental health supports available in your area

#### Community, Advocacy, and Activism

##### **Hamilton Mad Student Collective (HMSC)**

<http://www.hamiltonmadstudents.ca/>

##### **The Mental Health Rights Coalition of Hamilton**

<http://www.mentalhealthrights.ca/>  
Includes drop-in, peer support, and advocacy

##### **Mind Your Mind**

<http://mindyourmind.ca/>  
Online resource, including informative articles, opportunities for submission, and information about seeking mental health support

##### **Psychiatric Patient Advocate Office (PPAO)**

1-800-578-2343  
<http://www.sse.gov.on.ca/mohltc/ppao/en/default.aspx>  
Provides advocacy support for patients at Ontario’s 10 mental health facilities, including St. Joseph’s Hospital in Hamilton