# Exclusionary Structures: A Multi-Method Analysis of Structural Barriers Against University Students with Mental Health Challenges

by

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B.Sc., University of Saskatchewan, 2016
M.Sc., University of Victoria, 2018

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

#### DOCTOR OF PHILOSOPHY

In the Department of Psychology

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I acknowledge and respect the ləkwəŋən peoples on whose traditional territory the university stands and the Songhees, Esquimalt and WSÁNEĆ peoples whose historical relationships with the land continue to this day.

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#### Abstract

In dominant Canadian culture presently, it is taken for granted that "psy" professionals (e.g., counsellors, psychologists, psychiatrists) play a central role in the lives of individuals with mental health challenges. Indeed, much of the knowledge about mental illness is created by such professionals, and focuses on treatment and recovery. This focus has been costly, as it situates suffering within the individual, and ignores structural determinants of well-being. This results in structures that are exclusionary and discriminatory towards individuals with mental health challenges, which in turn makes it challenging for such individuals to achieve positions of power to influence knowledge production and systems. Although many forms of stigma exist, structural stigma refers to the policies of institutions and cultural norms within a society that intentionally or unintentionally limit individuals with mental health challenges' access to various rights, resources and opportunities. In this dissertation, I examined the presence of structural stigma towards individuals with mental health challenges at the University of Victoria in two studies. I used participatory practices, by having current and former University of Victoria students with mental health challenges as members of the research team throughout. In Study 1, current and former University of Victoria students (n = 275) completed a survey of structural barriers they had encountered, and reported on solutions and supports that were helpful. Seven dimensions of barriers were identified: 1) barriers in mental health care, 2) stigma and negative interpersonal interactions, 3) navigation of services barriers, 4) practical support knowledge barriers, 5) financial barriers, 6) learning barriers, and 7) inappropriate mental health services. Four dimensions of barriers specific to University of Victoria's Centre for Accessible Learning (CAL) were also identified: 1) helpfulness of CAL services, 2) misfit of CAL services, 3) disclosurerelated barriers, and 4) CAL administrative barriers. Upon follow-up analyses, these barriers

were inequitably distributed, disproportionately impacting marginalized students in various ways. Study 2 consisted of a multi-part World Café focused on barriers related to self-advocacy. Current and former University of Victoria students (n=21) discussed experiences of self-advocacy and solutions that could improve these barriers in rotating groups. I analyzed the data using thematic analysis, and identified three themes: 1) the structural context of self-advocacy, 2) the relational context of self-advocacy, and 3) rejecting self-advocacy. An additional discussion of short-term recommendations from participants is provided. To close, I reflect on the execution of participatory practices within this dissertation. I also discuss the implications of these results for broader anti-stigma agendas, and argue for community-centered approaches to supporting students with mental health challenges at university. Finally, I discuss the complexities and possibilities of taking action to better support students with mental health challenges at university.

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#### Acknowledgments

To my parents, your contribution is the hardest to put into words because it is everything: unwavering support in my pursuit of education and of this dissertation specifically, genuine interest in my work, steadfast belief in my abilities through countless periods of self-doubt, FaceTime calls on so many challenging days, home-cooked meals, and, for the last several months of writing this dissertation, welcoming me back home so I could focus on writing and spending time together. I am so lucky to have you both. To my sisters and brothers-in-law, for all of the outings, activities, interests, and conversations that have nothing to do with our work; it's all provided much-needed breaks and enriched my life immeasurably. To my niece and my nephews, it is in the light of your early lives that this dissertation was conceptualized and written. I mean this quite literally: much of this was written during your naps, or attempted to be written while you were awake, but many times I simply could not resist coming to play and see what amazing new things you had learned. To the one on the way, I can't wait to see the ways in which you change everything all over again. And to the one who departed: all of this would have been so for you as well. Your brief time here impacted me and this work greatly; you are remembered always and with so much love.

My work (and life) would not be the same without the solidarity I experienced among my colleagues. Clea Sturgess, Drexler Ortiz, Debra Torok, Jeremy Viczko, Kirsten Quistberg, Robyn Kilshaw: whether it was ten conversations or (in Clea's case) 10,000 conversations about our work, our lives, and anything else, your friendship made all the difference. Celine Brandt, gratitude always for your lifelong friendship, wherever our paths have taken and will take us. To my lab mates, each of whom made unique contributions to this work: Lorna Breen, enthusiasm and insights into the interpretation of findings; Lauren Matheson, careful attention and

observations, as well as discussion about participatory(ish) methods; Fanie Collardeau sent me the article that served as the initial spark for this dissertation, and inspires me each and every time we speak. Pauline Song, lab twin, your optimism and effusive encouragement have meant the world to me, alongside your invaluable feedback and our spirited discussions of the limitations of mental health systems.

Several professionals outside of my committee have played an essential role in this work. Dr. Jan Gelech, I am so lucky to have had your influence early on in my academic career, and I continue to aspire to the depth of understanding, empathy, and cultural critique that is evident in all you do. Dr. Andrea Piccinin, gratitude for your patient correspondence with me regarding the statistical methods used in this dissertation, and gratitude to Dr. Jessica Neal and Abby Matheson for embracing this project and for your commitment to helping us create change. Kim Monkman met with me early on to provide her perspective as a mental health nurse on this project, and provided invaluable connections with students with lived experience who informed this project. When our team talked about the type of service providers that are needed, we always returned to Kim as our example. Many student groups and professors on campus supported this work through allowing us to advertise our study. Such opportunities were often accompanied by encouraging words, which made all the difference.

This project was made possible through funding for me from the Social Sciences and Humanities Research Council of Canada, and for the research from the BC Support Unit, Vancouver Island Centre.

My committee played an invaluable role in the conceptualization and refinement of this research. Dr. Jamie Livingston, before we met, your writing on structural stigma provided the focus and direction for what would evolve into this dissertation. I am so grateful for the time and

energy you spent on this project, which has provided me with a much greater depth of understanding of structural stigma, and pushed me to reach greater theoretical coherence within the work. Thank you, as well, for your encouragement and belief in the participatory aspects of this work. Dr. Danu Stinson, your clarity of thinking and precise feedback on how to strengthen the fine details of this work helped push me to the next level. Special appreciation for how much time you spent helping me to refine my writing; it is feedback I will take forward. Appreciation, as well, for your practical suggestions for how to make this work achievable, both for me as a researcher and for those reading the work.

To Dr. Nev Jones, who serves as an external examiner on this dissertation: what an honour to have my work read and evaluated by someone with your depth of expertise. Your writings on the transformative potential of lived experience leadership have inspired me in this work and beyond, and your critique of this work will provide an invaluable source of growth.

To my supervisor, Dr. Erica Woodin, thank you for all your years of steadfast support: your discussion, your feedback, your wisdom, your encouragement. Thank you for your receptivity to my ideas and for letting me follow my interests and instincts over these seven years. It was your confidence in me that enabled me to grow and take risks in my research, all the while being assured that you would help me work through any challenges encountered.

To my former students and former clients: you are everywhere in this work. May you find opportunities in life that are worthy of all you have to offer.

To the team: I am humbled by how much of your time, your effort, your vulnerability, and your strength you dedicated to this project. Lucy Rohatynchuk and Camryn Anderson, though your time on our team was brief, your contributions and the space you created for our workshop participants was invaluable. Lucy, I am in awe of your passion and persistence in so

many areas of life, and Camryn, of your humour and independence. Sarah Jones, it was such an honour to have you join our team and wow us all with your warmth, your seemingly endless resourcefulness and your ability to solve complex problems with ease. To the three who were there from the beginning: Chelsea Colcol, Natalia da Costa, Maya Seymour. I cannot imagine doing this project with anyone else, and have been astounded by my good fortune at having a team of individuals who each have offered something so unique to this team: Chelsea, your precision in thinking and your courage in challenging yourself and our team; Natalia, your initiative and attunement to the needs of others; Maya, your ferocity in support of others and this project, and your refining eye to bring our work to the next level. Collectively, your work has made this project exceed what I imagined it could be, in outcome and in process, and my relationships with you have forever changed my perspectives. Thank you for buoying me and each other through the tough times we experienced during this project, personally and professionally, and for keeping the faith and enthusiasm in our vision.

#### **Chapter 1: Review of the Literature and Research Context**

In this dissertation, I aimed to explore and address structural stigma in post-secondary education among individuals with mental health challenges. Before turning to the specifics of the experience of post-secondary education for such individuals, important historical and current sociocultural context is needed. This introductory chapter: 1) explores the downsides of present-day "psy" dominance and the segregation of distress, 2) discusses the various forms of stigma and anti-stigma efforts currently taking place in North America and Europe, 3) summarizes the current state of the literature on higher education and those with mental health challenges, and 4) establishes researcher positionality and reviews best practices within participatory methods.

## "Psy" Dominance and its Present-Day Consequences

Presently, much of the research on mental health and social services in Canada is done by professionals, and typically involves those who use mental health services solely as research subjects (Landry, 2017). The present-day consequences of the dominance of "psy" professions in creating knowledge and treating mental distress have been far-reaching. In what follows, I will discuss the following consequences: 1) lack of attention to structural determinants of wellbeing, 2) perpetuating the dominance of institutional power, 3) the spread of "psy" discipline power into all aspects of life, 4) lack of diverse representation of individuals experiencing distress, and 5) narrowing of responsibility to individuals experiencing distress.

The first loss associated with a system of individual suffering and individual care, which rests upon adherence to the biomedical model, is a dire lack of attention to structural determinants of wellbeing. The focus on individual over structural factors has been termed "psychocentrism," and is seen as its own form of injustice as it promotes individual adaptation and coping for struggles and distress that are comprised as well of social, economic, political,

cultural, and/or historical facets (Dej, 2016; Rimke, 2016). This lack of attention is seen across research, practice, and news media (Costa et al., 2012; Holland, 2018). Systemic issues related to mental distress are widespread, and will be discussed in more detail later (see section "Structural Stigma"). Briefly, they include issues such as systemic poverty, lack of choice in services, maltreatment within various systems, services failing to ameliorate (or in some cases exacerbating) distress, and failures of governmental policy to meet basic needs such as housing, healthcare, and education (Costa et al., 2012; Frederick et al., 2017; Holland, 2018; Rimke, 2016). Notably, such individualistic narratives are perpetuated not just through stories that emphasize biomedical explanations for illness, but also those that emphasize recovery, as recovery narratives typically center aspects such as hard work, perseverance, and positive experiences within the mental health system, ignoring social, political, economic, and historical dimensions of distress (Costa et al., 2012; Holland, 2018; Pascal & Sagan, 2018).

Biomedical and individualized accounts of mental distress and recovery serve to further perpetuate and buttress individual treatment approaches, which occur across the "psy" disciplines. This is most obviously seen by the continued belief that the strongest evidence within the mental health field is quantitative evidence focused on treatment, above smaller scale qualitative studies about lived experience, participatory research designs, or survivor-controlled (i.e., research done by individuals harmed by or with lived experience with the psychiatric system) research (Faulkner, 2017). However, studies that purport to "involve" service users to various extents can be, and often are, also problematic in their use of individual stories to bolster institutional support. To educate both service users and clinicians about the dangers of service user involvement in research, Costa and colleagues (2012) held a workshop in Toronto entitled "Hands Off Our Stories." Costa and colleagues (2012) note that storytelling began in the 1980s

and 1990s as an act of resistance for those who had experience in the psychiatric system to share their lived experiences and demand they be taken seriously. Over time, the 'psy' disciplines have co-opted this practice and now "absorb," "sanitize" and individualize service user stories as a means to bolster support from politicians, the public, and philanthropists for their organization (Costa et al., 2012; Holland, 2018; Pascal & Sagan, 2018). In short, the collection and distribution of service user stories is for the benefit of the organization, not the client. Costa and colleagues (2012) term this process "patient porn," as some are revealing intimate details of their life for the relief of others by promulgating that the status quo is working adequately, and no systemic change is needed. A similar trend is also noted in media, where media stories of mental distress tend to perpetuate dominant "psy" practices, and in fact may imply that it is dangerous to present information that goes against "doctor's orders" (Holland, 2018). As a result, there is little space in research, practice, or dominant discourse for stories of activism and systemic injustice (Costa et al., 2012; Holland, 2018).

Due to the dominance of "psy" discourses and institutions, it can now be seen that the power of these institutions extends beyond the institution themselves and into everyday life. This can be explained by Foucault's (1991) concept of Panopticism, where the power to monitor for desired behavior extends beyond formal institutions and into multiple types of professionals (e.g., social workers, doctors, psychologists, psychotherapists), and into family, friends, and the person themselves (Roberts, 2005; Swerdfager, 2016). This can be seen in training and information given to the public at large which encourages them to refer those they see exhibiting certain behaviors into the "psy" institutions (de Bie, 2019; DeFehr, 2016). Ultimately, this distributed power leads most in dominant Western culture to self-monitor for alignment with "psy" understandings and ideals, leading to individual angst as people evaluate whether they

possess the self-managing capacities necessary for achieving "success" as it is currently defined, and, if not, take action to attain such capacities (Rose, 1999). Rose (1999) discusses that this distributed power is intentional, as it allows governments to predominantly act on citizens lives and goals from afar. That is, rather than coercing individuals to align with broader societal goals of consumption, profitability, efficiency, and social order, "psy" dominance shapes how individuals think about their life options and what constitutes a "good life" in a way that aligns with these goals (Rose, 1999). Thus, "psy" discourses can be seen as dictating and controlling what a person understands themselves to be, and what others understand them to be, with this power existing not solely in formal institutions but being distributed in the community and in individuals (Roberts, 2005; Rose, 1999). Importantly, this distributed monitoring and correcting is only possible due to relationships of power, where it is seen that the thoughts, rights, and actions of the non-Mad are privileged over the Mad, and the thoughts, rights, and actions of the experts are privileged over patients (Swerdfager, 2016).

This distributed monitoring, combined with the wide use of patient experience to perpetuate institutional power, has led to a situation where only particular patient experiences are heard and seen in public and academic discourse. In news and public representations of people with mental health challenges, it is felt that those represented are often "young, attractive, recovered, compliant with biomedical authority and/or celebrities" (Holland, 2018). Pascal and Sagan (2018) describe how those who choose not or are unable to participate in either research or public discourse about mental distress have their experiences erased. On the oppressive nature of recovery narratives, they write:

The *responsibility* to recover and, in the words of one of our participants to 'speak wellness' may be experienced by some as an empowering spur to self-efficacy... Yet the lost

experiences of those who fail to recover, to enter remission; or even stoically narrate their journey to us as interviewers may thereby be further stamped with desolation and futility. If such recovery and coping narratives are perpetuated in the absence of a range of health resources the recovery movement and its allied research unwittingly aligns with the neoliberalization of health care. (Pascal & Sagan, 2018, p. 263).

This dominance of particular types of narratives of distress corresponds to the creation of "master narratives" and "majoritarian stories" about racial/ethnic identities (Shin, 2015). Briefly, the creation of narrow stories about people experiencing distress works to create beliefs that there are essentialist differences and realities between categories of people that are socially constructed. This belief that there is a specific way to *do* and *be* distressed not only erases the complexity of experience, but also further perpetuates sanism by reifying "us" and "them" categories (Shin, 2015).

Further, because mental health research is dominated by such highly specialized professionals, research and knowledge generated tends to focus solely on treatment and rehabilitation. There is relatively little representation of individuals with lived experience within positions of intellectual power, meaning there is a lack of knowledge generated about the culture, history, art, and identity of individuals with mental health challenges, which further positions such individuals as those who solely needs professional help, rather than someone who can make unique contributions to a community (Jones & Brown, 2012).

The minimization of the role of structures in wellbeing and the dominance of particular, curated "psy" discourses of distress in daily life among both professionals and non-professionals has resulted in a lack of broader sense of responsibility to individuals experiencing distress in communities. As written by Kruse and Oswal "At the root of these issues is... the ableist

assumption that disability is over there, not here and that mental disability is a special circumstance requiring special care, not a part and parcel of everyday human life, and therefore, societal life" (2018; p. 199). Community members are taught that the most supportive act they can take for an individual experiencing distress is to refer them out for professional services (de Bie, 2019). Walker and colleagues (2017) have critiqued the 'psy' professions for eroding the dignity and value of "ordinary wisdom" that all of us have about the issues, big and small, that we encounter in life. Although not arguing that professional mental health services are wholly harmful per se, the unintended consequences of the dominance of such services have been serious. Specifically, Walker and colleagues (2017) write:

One of the major casualties of the activities, technologies, and enclosures of the traditional psy disciplines has been our collective responsibility and capacity to heal and support ourselves and others simply as human beings. The psy disciplines have, in the process of privileging professional understandings of distress, potentially facilitated a corrosion of the dignity of 'lay' human selfhood where human beings in the West no longer have any sense of public agency in the understanding and amelioration of distress. (p. 47)

This erosion of collective responsibility to individuals experiencing distress perpetuates and exacerbates ongoing "psy" dominance, as wellness becomes something that is achieved through professional help, as opposed to through ongoing personal relationships and solidarity.

Though specific details regarding the state of knowledge about higher education for students with mental health challenges will be reviewed later in this chapter (see Section "Higher Education Experiences of Individuals with Mental Health Challenges"), a brief theoretical overview about how "psy" dominance influences both the higher education experiences of

students with mental health challenges, as well as the knowledge generated about experiences will be provided here. First, one would expect psychocentrism to permeate higher education experiences and knowledge through a dominance of services that focus on symptom reduction and student adaptation to ableist post-secondary practices, as opposed to meaningful knowledge generation and practice aimed at dismantling inaccessible structures. One would further expect any narratives about students with mental health challenges and presented by such institutions to contain elements of perseverance, hard-work, individual recovery, and typical treatment trajectories including therapy and medication. Such narratives may bolster the post-secondary institution's reputation and the reputation for the quality of services provided to students, and in the process de-collectivize and sanitize student experiences of marginalization and resistance.

The dominance of "psy" understandings certainly permeates post-secondary settings, and thus students with mental health challenges are likely to experience distributed monitoring within post-secondary settings, where instructors, service providers, other students, and the student themselves are all trained to monitor the student for signs of deviance from widely embedded "psy" norms. These individuals are then tasked with referring to services or seeking support to help the student re-align themselves with dominant understandings and ways of being, without making alternatives accessible. Failure to do so may lead to beliefs that the student cannot succeed in post-secondary education. One would expect the perpetuation of such dominant narratives to render invisible those who may have different experiences, pathways, and goals within post-secondary education. Such invisibility of diverse experiences would create and recreate "us" and "them" categories between those with and without mental health challenges, thus reifying socially constructed categories and simultaneously homogenizing (i.e., students with mental health challenges have the same experience/needs) and individualizing (i.e., student

success or failure is based on an individual's efforts or symptoms, as opposed to structural accessibility) a diverse group of individuals and experiences. The result of this is the construction of students with mental health challenges as "out there," creating a special category of experience that calls for separation and treatment by professionals, rather than a human experience that calls for diverse and multiple forms of formal and informal respect, care, and inclusion.

As a result of these forces, one could expect, then, the existence of unresponsive systems and exclusionary practices that are rarely examined or altered, because the dominance of individual interpretations of wellness and illness, and success and failure, obfuscate the need for such attention. Without such attention to systemic discrimination, post-secondary education remains largely inaccessible to and intolerant towards students with mental health challenges, thus making it exceedingly difficult for students with these experiences to succeed and attain the power necessary to shift narratives and experiences, and thus the cycle continues.

# The Stigmatization of and Discrimination Against Individuals with Mental Health Challenges

With an understanding of the current dominant state of understanding of mental health challenges, we can now turn to a more specific discussion of the marginalization of individuals who struggle with their mental health. When discussing stigmatization, one must first attend to the function and purpose of stigma. Though I will use the word "stigma" throughout this section since it is the most common and easily recognized terminology, it has convincingly been argued that the word "discrimination" be used rather than stigma, as discrimination shifts the onus from the individual experiencing discrimination to the one(s) perpetrating (Linz & Sturm, 2013). I

would add that the word "stigma" can erase the societal conditions that cause one to be stigmatized.

When researchers account for stigma, it is often at the individual level in terms of what stigma is "felt," or how stigma and discrimination are enacted by individuals, rather than by examining the broader context of how stigma is created and re-created, and the functions of stigma in context. Thus, I aim to conceptualize stigma in a way that incorporates these ideas. My conceptualization is aligned with Link and Phelan's (2001) definition, which suggests that stigmatization occurs when the following contextual elements are present: 1) a human difference is labelled, 2) cultural beliefs and norms link the labelled difference to negative stereotypes, 3) labeled persons are categorized, creating an "us" and "them", and 4) labeled persons lose status and experience discrimination. The overarching context for such stigmatization to occur relies on individuals from different groups having unequal access to social, economic, and political power, in that groups who dominate these power structures control the labeling, negative stereotypes, and unequal treatment that occur within stigmatization (Link & Phelan, 2001).

It has been argued that stigma and its perpetuation allows for "the structures, mechanisms, and justifications of power to function" (Link & Phelan, 2014). For example, it was noted by participants in an evaluation of news stories on mental illness that the way these stories (e.g., individualistically, creating danger and mistrust around mental illness) are framed aligns with larger government goals of constructing certain segments of the population as taxpayer burdens, thus reducing support for policies such as housing and disability income (Holland, 2018). Thus, stigma should not be seen as a seemingly random, uncontrollable "thing" that happens between people, but a purposeful set of attitudes and scripts constructed in the context of power to provide systemic justification for discriminatory policies, unequal distribution of

resources, social exclusion, and public acceptance of violations against a certain group of persons (Tyler & Slater, 2018). Thus, stigma is created and exists not due to an attribute being inherently problematic, but rather due to complex social processes that occur in broader cultural and historical contexts (Livingston, 2013).

These broader stigmatizing narratives impact society at several intersecting levels: public, structural, and self. First, there is public stigma, which, applied to mental distress, are the negative attitudes of the general public towards individuals with mental health challenges (Charles & Bentley, 2016). Such public stigma can be enacted both through action (e.g., discrimination, violence) and inaction (e.g., invisibility, failure to protect) (Livingston, 2013). Structural stigma refers to the policies of institutions and cultural norms within a society that intentionally or unintentionally limit individuals with mental health challenges' access to various rights, resources and opportunities (Charles & Bentley, 2016; Hatzenbuehler, 2016; Livingston, 2013). Such stigma is seen through, for example, a lack of availability of services to address mental illness, as well as limited access to housing, education, and employment (Livingston, 2013). Internalized stigma occurs when individuals with the stigmatized attribute internalize their devalued status in society, which may lead to low expectations for the self, and a hesitancy to challenge systemic barriers (Livingston, 2013). In this section, I will provide a brief overview of each of these forms of stigma and ongoing issues relevant to each form.

### Public Stigma and Modern-Day Anti-Stigma Interventions

There is clear evidence that individuals with mental health challenges continue to be constructed as Other (Walsh & Foster, 2020), and prevailing stereotypes of individuals diagnosed with serious mental illnesses include that they are dangerous, unpredictable, lacking of capacity for "rational" thought, that they are to blame for their distress, that they should be

treated with an attitude of benevolence and paternalism, and that they have a poor prognosis (Charles & Bentley, 2016; Leblanc & Kinsella, 2016; Stuart & Arboleda-Flórez, 2012). Such stereotypes have been termed "sanism" (Leblanc & Kinsella, 2016), and these stereotypes have increased over time, specifically towards individuals diagnosed with psychotic illnesses (Stuart & Arboleda-Flórez, 2012). Endorsement of such stereotypes are associated with public preferences for a range of structural discrimination including coercive treatment, and acceptance of social inequities, injustices, and human rights violations (Stuart & Arboleda-Flórez, 2012). Importantly, the pervasive presence of sanism makes it acceptable or, in some cases, seen as right or necessary to treat individuals with mental health challenges poorly through behaviours such as exclusion, microaggressions, rejection, silencing, and violence (Poole & Grant, 2018).

Thus, there is a clear need for societal attitude changes towards individuals with mental health challenges, and it is indeed public stigma that most anti-stigma campaigns target. Keeping in mind the role that stigma plays in society (i.e., justification for the status quo), it is particularly interesting to interpret the existing evidence for purportedly "anti-stigma" campaigns. One can often see three common themes in many anti-stigma campaigns today: 1) that mental illnesses are illnesses like any other, 2) that we need to change our language around mental illness, and 3) that stigma must be reduced to decrease shame and thus stimulate increased help-seeking from mental health professionals. First, anti-stigma campaigns often focus on messaging about mental illnesses being brain-based disorders (Corrigan, 2016). Unfortunately, the evidence suggests that beliefs that mental illness is a brain disorder are associated with a range of negative beliefs and behaviors such as beliefs that people with mental illnesses are dangerous and incompetent, greater desire for social distance, and beliefs that people with mental illness will not recover,

which is in turn predictive of whether an employer will hire someone or a landlord will rent to someone (Corrigan, 2016; Morgan et al., 2018; Stuart & Arboleda-Flórez, 2012).

Second, a focus on language (e.g., changing from saying "schizophrenic" to "person with schizophrenia") is central in modern-day anti-stigma campaigns (e.g., Bell Let's Talk, 2019). Such an approach has been warned about, as it is noted that, for example, the shift in use of language to Black or African American from more offensive terms in the United States did not end discrimination, but rather made the language more disguised and palatable (Corrigan, 2016). As Mad activist Judi Chamberlin wrote "Mental patients are stigmatized not by language, but by the fact that it is legally acceptable to treat them differently. The 'stigma' of mental illness does not flow from the use of words, and cannot be changed merely by changing the language" (Chamberlin, 1977, n.p.).

Third, many present-day anti-stigma campaigns focus on a services agenda, which takes as its aim the reduction of stigma in order to increase help-seeking behavior among people experiencing distress (Corrigan & Al-Khouja, 2018). Such an agenda rests on the assumption that engaging in mental health services is central to helping individuals manage their symptoms and accomplish their personal goals. As such, we can see how this agenda, although purportedly aiming to help those in distress, is most certainly helpful to bolster support for "psy" institutions in a similar way to how patient stories are co-opted to provide support for institutions (Costa et al., 2012). It has been further pointed out that some campaigns that take a services agenda (e.g., Heads Together in the UK), seek to de-stigmatize help-seeking without addressing the lack of appropriate, accessible, and high-quality services, thus putting it onto the individual to seek out and acquire services from a strained and inaccessible system (Tyler & Slater, 2018). Thus, it is suspect whether these three common messages in anti-stigma campaigns are effective in

addressing or improving the conditions of individuals with mental health challenges. However, these messages help to perpetuate neoliberal (i.e., an ideology that constructs all dimensions of life in terms of market rationality, thereby reducing funding across domains and increasing work, productivity, and personal responsibility; Birch, 2017) views of mental illness and secure beliefs that social inequities are justified, and that coercive, mandated treatments and professional assistance with individual solutions are needed, thus perpetuating the status quo. Here, one can see the importance of looking at the broader function that both stigma and reportedly anti-stigma efforts can play in perpetuating and garnering support for inequitable systems (Tyler & Slater, 2018).

Several other approaches to public anti-stigma work have garnered more evidentiary support. The first is contact in the form of face-to-face interventions. Contact between individuals with mental health challenges and those without has been shown to exert positive changes in attitudes and behavioral intentions, although it is unclear how long such changes last (Corrigan, 2016; Morgan et al., 2018). For example, it was reported in a recent meta-analysis that, although contact interventions significantly reduced stigmatizing attitudes and desire for social distance immediately post-intervention, this effect does not remain significant eight weeks later (Morgan et al., 2018). Evidence suggests that an emphasis on stories of recovery (i.e., reduction in symptoms, return to "normal" functioning) is key to successful contact interventions (Morgan et al., 2018). Interventions that focus on education aligned with models of illness and wellness put forth by "psy" disciplines (i.e., either genetic/biological attributions or psychological attributions for distress) also show change in attitudes for up to six months following intervention (Morgan et al., 2018).

At this point, it is worth reflecting on the goals of anti-stigma agendas. One can see that, even within strategies that are "effective" for reducing stigmatizing attitudes such as contact and education, there is still a qualified acceptance in that these interventions center dominant biomedical understandings of distress and center recovery narratives (Morgan et al., 2018). As discussed earlier, this perpetuates the limited representation of what an "acceptable" person with mental health challenges is and excludes intra-group diversity of experience and understanding (Pascal & Sagan, 2018). Further, such approaches rely on people without mental illness' willingness and interest to go to a "special" place to learn about the "special" case of mental illness. Within time-limited educational interventions and contact-based interventions, there remains no true ongoing relationship and interaction that permeates into everyday societal life. Thus, though contact and education may, at least temporarily, decrease public stigma, one must attend to what concessions people with mental health challenges are asked to make, and if those concessions are, in fact, helpful in the broader struggle for justice.

As this project pertains specifically to post-secondary education, it is important to take note of how public stigma and anti-stigma campaigns appear in this setting. First, in Canada, dominant anti-stigma campaigns such as Bell Let's Talk commonly have a post-secondary presence, with this particular campaign being present at over 225 post-secondary institutions across Canada in 2022 (Bell Let's Talk, 2022). Such broad awareness campaigns have been criticized for rarely being evaluated (Corrigan, 2012; Vyncke & Van Gorp, 2020), and thus little is known about how post-secondary students and staff react to mental health awareness messaging. The results from one Canadian study suggest that, although such campaigns are appreciated, they are seen as only one step towards improving the post-secondary experience for

students with mental health challenges, with structural change being emphasized as a necessary further step (Giamos et al., 2017).

Post-secondary institutions often have other student and university-led groups and committees to address mental health stigma. For example, the University of Victoria has the student-led "UVic Students Above Stigma" and "UVic Mental Health Awareness Club," and at an institutional level has a Student Mental Health Strategy, which has one aim centered around addressing stigma (University of Victoria, n.d.). Such groups generally discuss de-stigmatizing mental health challenges through raising awareness of stigma, suggesting an understanding that stigma is a belief that needs to be changed, aligning with understandings of public stigma. Again, the work of such groups is often applied with little knowledge of potential impact or applicability for students, and thus it is unknown whether such efforts impact the student experience.

Alternatively, the undergraduate population is often used as a starting point for evaluation of anti-stigma interventions. Generally, these findings align with mental health stigma efforts in the general population, including that social or video-based contact interventions reduce desire for social distance, and that contact and education-based interventions improve attitudes towards mental health services and help-seeking (Kosyluk et al., 2016; Shahwan et al., 2020; Yamaguchi et al., 2013). Thus, overall, it appears that the same limitations in scope of intervention and knowledge of impact exist in public stigma efforts that take place within post-secondary institutions as those that take place in the general population.

### Structural Stigma and the Rights Agenda

There are, of course, other focuses that can be taken by anti-stigma campaigns.

Specifically, until this point I have discussed anti-stigma approaches that target public stigma.

Alternatively, anti-stigma campaigns could target structural stigma. It has been highlighted that

anti-stigma campaigns for other stigmatized attributes, such as the use of wheelchairs, do not center the cause of difference as relevant (Stuart & Arboleda-Flórez, 2012). Instead, they have focused on the right of such individuals to be included in social and economic life, regardless of the reasons for why an individual may need a wheelchair. Thus, a more effective means to reduce stigma may focus on removing social, organizational, and other barriers to social and community inclusion (Stuart & Arboleda-Flórez, 2012). This alternative, structural stigma-focused agenda has been termed the "rights" agenda, and takes as its focus helping people achieve their rightful goals. Such an agenda focuses more strictly on institutional forms of stigma and discrimination, and challenges laws, policies, and practices that deprive individuals of housing, educational, and work opportunities (Corrigan & Al-Khouja, 2018). Notably, this rights-based focus would circumvent several issues encountered in other anti-stigma efforts, including the requirement for people with mental illness to fit a certain box (e.g., recovered, compliant) in order to not be stigmatized. Rights efforts do not focus on a person achieving certain prerequisites in order to be "deserving" of those rights.

At this point, then, it is warranted to discuss where structural stigma exists for individuals with mental health challenges. Structural stigma does not necessarily exist in all policies and procedures that result in differential treatment between groups, as at times differential treatment is necessary in order to adequately support people's varying needs (Livingston, 2013). Specifically, structural stigma towards individuals with mental health challenges exists in Canada in 10 intersecting domains: 1) healthcare, 2) employment and income, 3) housing, 4) education, 5) criminal justice, 6) privacy, 7) public participation, 8) travel and immigration, 9) media, and 10) reproduction and parenting (Livingston, 2013). As my focus is on structural stigma in education, this will be reviewed in depth later in this dissertation proposal (see

"Structural Stigma in Higher Education"), with some examples of structural stigma in education being failure to provide appropriate academic accommodations, inaccessibility and unaffordability of assessments to "prove" disability and therefore grant access to support, and discrimination against those who disclose mental illness in their applications for university (Chambers, Bolton, & Sukhai, 2013; Livingston, 2013; Zöld, Swift, Penix, & Trusty, 2020). However, it is important to note that the various domains of structural stigma do not exist in silos, and thus one is not exempt from, for example, experiencing structural stigma in healthcare or housing solely because one is a post-secondary student. In fact, multiple experiences of structural stigma may intersect and compound exclusion as, for example, inadequate access to housing and healthcare are likely to make success in post-secondary institutions more challenging. Further, specific domains such as lack of privacy may exist within multiple forms of structural stigma, such as experiencing coercion to disclose experiences in order to access necessary services, and increased surveillance by various professionals once a diagnosis is known (Livingston, 2013). Thus, although structural stigma in post-secondary education is the focus of this dissertation, it is likely that action in different domains of structural stigma would indirectly impact post-secondary access and experiences.

#### Consequences of Stigma and Internalized Stigma

There are a range of individual consequences of mental illness stigma. Both in research and public anti-stigma campaigns, perhaps the most commonly discussed consequence is how stigma negatively affects individuals' willingness to reach out for and accept help (e.g., Clement et al., 2015; Henderson et al., 2015; Schnyder et al., 2017). For example, the Bell Let's Talk campaign's main website reads "Stigma can prevent those struggling with a mental illness from seeking the help they need" (Bell Let's Talk, 2019). Such concerns can generally fall under the

concept of "label avoidance," where individuals avoid seeking treatment because of the real and significant social consequences that are associated with becoming (and being seen by others as) a "mental patient" (Corrigan, 2007). Elyn Saks, a professor of law, psychology, and psychiatry who is diagnosed with schizophrenia, illustrates this in her memoir by stating her early belief, which led her not to adhere to her medication, that "the less medication I took, the less defective I was" (2007, p. 252). There are a range of other ways in which stigma impacts the lives of individuals with mental health challenges. In a national survey in the United States, 74% of individuals avoided disclosing mental illness outside their immediate family, 71% denied having mental illness on applications for fear of discrimination, and 31% were turned down for a job for which they were qualified once they disclosed mental illness (Wahl, 1999). Internationally, 47% of people diagnosed with schizophrenia report experiencing discrimination, and 72% felt the need to conceal their diagnosis (Thornicroft et al., 2009). In Canada in 2012, 18% of individuals diagnosed with mental illness reported that stigma impacted their housing, 25% their financial situation, 28% their work or school life, 30% their romantic life, and 32% family relationships (Stuart & Arboleda-Flórez, 2012). It is important to be mindful as well that multiple oppressed identities play a role in the experience of mental health stigma. Pre-existing discrimination based on race, class, or sexual orientation, for example, can intensify the experience of stigma associated with mental health difficulties (Kidd et al., 2018; Tew et al., 2012)

For individuals with mental health challenges, there is also the issue of internalized stigma, where individuals are aware of stereotypes, agree with stereotypes, and apply the stereotypes to themselves. Internalized stigma allows for the perpetuation of structural stigma, as it keeps stigmatized groups from recognizing and feeling empowered to speak to experiences of discrimination (Link & Phelan, 2014). Internalized stigma can also be seen through internalized

beliefs that individuals with mental health challenges should be able to regulate and manage themselves and participate in communities that are structurally exclusionary (Frederick et al., 2017). For example, a study of homeless individuals in Ottawa revealed that such individuals were strongly against "blaming the environment" for their circumstances as they saw accounting for social, historical, and cultural factors to be "making excuses" (Dej, 2016). These individuals felt more comfortable with individual, "psy" based explanations for their situations. A similar struggle to move away from individualistic framing, even in light of naming experiences of racism, sexism, and sanism, was seen among participants involved with mental health services (e.g., service users, professionals, family members; Morrow & Weisser, 2013). This is further perpetuated by efforts to decrease internalized stigma, which typically focus on education or providing cognitive behavioral strategies to manage negative self-thoughts as opposed to naming experiences as prejudice and discrimination (Mittal et al., 2012).

At the intersection of public, structural, and internalized stigma is epistemic injustice. Essentially, epistemic injustice occurs when one is denied their status as someone who can "know," including their ability to be heard as they share their own understandings of their lives (Leblanc & Kinsella, 2016). There are two forms of epistemic injustice: testimonial and hermeneutical. Testimonial injustice is when individuals cannot be heard because the hearer has identity prejudices towards the individual such as, for example, that the speaker is not credible or lacks insight (Leblanc & Kinsella, 2016). Hermeneutical injustice is when groups of individuals lack social understanding due to structural prejudice which limits the access to and number of resources to interpret one's life (Leblanc & Kinsella, 2016). For example, the dominance of biomedical discourses could be seen as resulting in hermeneutical injustice, as its dominance severely limits the interpretive resources individuals with mental health challenges have to make

sense of their own experiences. Hermeneutical injustice makes it possible for prejudice and discrimination to go unchecked, as both the discriminator and the one being discriminated against lack the resources needed to interpret an experience as discriminatory (Leblanc & Kinsella, 2016). Hermeneutical injustice clearly limits both individual and broader community abilities to discuss and understand fully what it is like to exist with mental health challenges presently. As described by Fricker (1999):

When our practice is uninformed by the experience of people in a given social position, we are collectively in a position fully to understand neither the experiences in question, nor any other areas of the social world to which they have interpretive relevance. Thus some people's social experience remains obscure and confusing, even for them, in a way which limits or distorts collective social understanding more generally. (p. 208)

In this way, epistemic injustice allows stigma and discrimination to persist, because it edits out the language of stigma and discrimination itself and replaces it with beliefs of unreliability, lack of insight, and need for enforced treatment.

## Higher Education Experiences of Individuals with Mental Health Challenges

With a thorough understanding of the limitations of current public discourse and the various ways in which the marginalization of individuals with mental health challenges is created and maintained, it is now possible to turn to post-secondary experiences of individuals with mental health challenges. Higher education has both a personal and societal role to play in ameliorating the ongoing inequities and discrimination experienced by individuals with mental health challenges. There is ample evidence that the personal experience of attending higher education is important for individuals with mental health challenges as the experience can provide a sense of purpose, can be a catalyst for exploring identity, and can improve quality of

life and future employment prospects (Knis-Matthews et al., 2007; McAuliffe et al., 2012; Megivern et al., 2003; Moriña, 2017; O'Shea & Kaplan, 2018). More broadly, it has been argued that stigma is a fundamental cause of population health inequalities (Hatzenbuehler et al., 2013). Specifically, it has been argued that because stigma is clearly linked to both physical and mental health outcomes, and to access to structural, interpersonal, and psychological resources that may be used to minimize negative health outcomes, it can be considered one of the forces that, across time, leads to inequitable health outcomes between groups (Hatzenbuehler et al., 2013). Thus, active attempts to dismantle structural stigma, including that which occurs in post-secondary education are necessary if equitable social outcomes are to be achieved. Post-secondary education may be a particularly powerful venue for challenging structural stigma, as a greater presence of individuals with mental health challenges in higher education increases representation in positions of power, thus increasing access for individuals in this group to guide knowledge production and therefore influence societal views and attitudes toward individuals with mental health challenges (Jones & Brown, 2012). Thus, equitable access to post-secondary education for individuals with mental health challenges is important in terms of personal fulfillment, access to resources to improve health outcomes, and for power and knowledge redistribution. Over long periods of time, the intention is that such shifts can foster equity between individuals with and without mental health challenges, and reduce multiple forms of stigma.

Though this section will outline overall trends and themes of experience of individuals with mental health challenges in post-secondary education, there is great variability, and it has been noted that students with mental health challenges desire to have their personal experiences and preferences in relation to higher education and support experiences taken into account (Fossey et al., 2017; Mullins & Preyde, 2013). Thus, though trends will be outlined, these should

not be taken as representative of the experiences and desires of all post-secondary students with mental health challenges. This section will first provide a brief overview of the state of the literature on higher education for individuals with mental health challenges including highlighting major ongoing issues and what is known about supportive strategies, and will close by outlining structural stigma in higher education.

### Ongoing Challenges in Higher Education for Individuals with Mental Health Challenges

There are several areas of research regarding challenges and issues that individuals with mental health challenges have in navigating higher education systems. These are: 1) exclusion and stigma, 2) disclosure, 3) symptom interference in academics, 4) lack of knowledge of supports, and 5) other life stressors.

There is evidence of stigma and discrimination against individuals with mental health challenges in post-secondary education. In fact, it has been noted that "pervasive social stigma" is a risk factor for the successful completion of post-secondary education among individuals with mental health challenges, and stigma and negative stereotypes are perhaps the most frequently cited barrier to higher education in the literature (Hartley, 2010; Stein, 2014). This is linked to constructions of university as places not just for the "normal," but for the exceptional and elite; the ongoing dynamics of university are to elevate a few, and thus exclusionary practices may at times be accepted or encouraged (Dolmage, 2017). Overall, students with mental health challenges report poorer relationships with fellow students, faculty, and administration as opposed to students without, with a significant proportion of students reporting experiences of social isolation (Megivern et al., 2003; Salzer, 2012).

There are a range of negative attitudes towards students with mental health challenges at university. Both nondisabled students and faculty endorse more favorable opinions for

integration of and greater beliefs of success for students with physical and sensory disabilities as opposed to those with mental illness (Cox, 2017; Hartrey et al., 2017). Because mental health challenges can be more ambiguous in terms of diagnosis, and appropriate support and intervention, when a student with mental health challenges fails to improve when supports are rendered, they may be more likely to be labeled as resistant or dishonest as opposed to requiring further consultation and support (Cox, 2017). Faculty also report beliefs of dangerousness, feelings of discomfort, and concerns that students with mental health challenges have poor judgment (Brockelman & Scheyett, 2015; Hartrey et al., 2017). Mental illness stigma differs at the intersection of various identities with, for example, anti-Black sanism referring to the unique form of oppression that is experienced by Black or African identified individuals, including an overrepresentation of schizophrenia diagnoses among young Black men and higher rates of involuntary hospitalization for Black people (Meerai & Poole, 2016). In general, a range of other stereotypes of mental disability may be present, including that disability is a constant, fixed state, that individuals with disability are in need of help and assistance at all times, that mental disability can and should be "cured," and that disability is a result of individual characteristics, and does not have contextual components (Kruse & Oswal, 2018). Interestingly, post-secondary students who have a mental health challenges themselves or who have a friend or family member with mental health challenges express lower desire for social distance, but report the same levels of perceived dangerousness as those without close contact with mental illness (Markowitz & Engelman, 2017).

There is also evidence of skepticism of the reality of mental distress experiences.

Students with mental health challenges report faculty doubting the student has a disability, especially as mental distress is an invisible disability (Magnus & Tøssebro, 2014; Moriña, 2017;

Mullins & Preyde, 2013). In fact, students report being seen by faculty as more "deserving" of accommodation when they have a visible, as opposed to invisible, impairment (Magnus & Tøssebro, 2014). This results in faculty beliefs that students with mental health challenges are seeking "special treatment," as opposed to necessary supports, when accessing accommodations (Dolmage, 2017; Mullins & Preyde, 2013; Padron, 2006). Although there is clear evidence that faculty doubt the validity of providing accommodation for individuals with mental health challenges, faculty also hold beliefs that students with mental health challenges are not able to meet the academic, practicum, and social requirements of students (McAuliffe et al., 2012). Thus, students who disclose mental illness may find themselves in a double bind, as there are competing stereotypes that they are both ill-suited to and incapable of success in higher education (Kruse & Oswal, 2018), and that they are being difficult by exaggerating everyday problems in order to receive special treatment (O'Shea & Kaplan, 2018; Reid & Poole, 2013; Stein, 2014).

Further, the invisible nature of mental health challenges means that at times students hear fellow students or professors express negative attitudes about students with mental health challenges, such as beliefs about instability, comments that belittle the severity of distress experiences, or comments that students with disabilities do not belong at university (Mullins & Preyde, 2013). Overall, the way mental distress is taught in universities is heavily focused on medication and treatment, and creates a dichotomy of "us" (the rational students) learning about "them" (irrational clients/patients), rendering invisible the reality that individuals can and do occupy both roles (Reid & Poole, 2013). Thus, not only is stigma present in faculty and fellow students, but also the invisibility of mental illness means that affected students may be

particularly likely to hear these negative stereotypes and beliefs from others who are not aware they are speaking to someone with mental health challenges.

Based on these experiences of discrimination, exclusion, and invisibility, it should come as no surprise that students with mental health challenges suffer a range of psychosocial consequences. These include feelings of embarrassment, rejection, low self-esteem, not wanting to stand out, and fears of being seen as inadequate (Kain et al., 2019; Markoulakis & Kirsh, 2013). Such experiences may also disrupt academic goals by leading students to withdraw from activities such as attending class, group work, and campus social activities for fear of having others discover their diagnosis or experiences of distress (Markoulakis & Kirsh, 2013). Some individuals opt out of accommodations, or use them despite feeling shame and embarrassment, for fear that using accommodations will signal their diagnosis to other students (Mullins & Preyde, 2013; Venville et al., 2014b). The secrecy about mental distress within higher education can also lead to loneliness and a sense of invisibility, as students with mental health challenges are often unable to connect with and share experiences with each other (de Bie, 2019; O'Shea & Kaplan, 2018). Further, the forms of knowledge that Mad students may use in educational settings, such as emotion or personal disclosure, may be interpreted as signs of "risk" rather than valid knowledge being shared (de Bie, 2019).

In the context of this stigma and discrimination, decisions about whether and to whom to disclose has become the focus of a large body of research. Disclosure decisions are especially important as the provision of services and accessibility efforts currently require student willingness to disclose. These decisions are complicated, as students must decide both whom to disclose to and what level of detail to share (Fossey et al., 2017). Fear of disclosure is commonly noted for reasons such as wanting to avoid stigma, worries about being seen as deceptive, and

fears of negative impacts on relationships and future career prospects (Hartrey et al., 2017; Kain et al., 2019; Lindsay et al., 2018; Magnus & Tøssebro, 2014; Markoulakis & Kirsh, 2013; Padron, 2006; Venville et al., 2014b). In light of the previous discussion of discrimination and exclusion on the basis of mental illness diagnoses, these fears are warranted.

Importantly, experiences of disclosure appear confusing and unclear for both faculty and students, and students often have mixed experiences when disclosing. Faculty express uncertainty about how to respond to disclosures (McAuliffe et al., 2012), and students report confusion who they should disclose to, what happens with information they disclose, and who would have access to this information (McAuliffe et al., 2012). Thus, some students choose not to disclose based on a history of discrimination following from disclosure or fear of future negative consequences, while others report some instances of supportive and understanding responses from professors and students (Knis-Matthews et al., 2007; Kranke et al., 2013; Magnus & Tøssebro, 2014; Venville et al., 2014b).

Several factors influence the likelihood students will disclose. Importantly, rapport and prior positive interactions with professors make students more likely to disclose (Lindsay et al., 2018; Magnus & Tøssebro, 2014; Venville et al., 2014b). Availability of supports, disability type, and extent of self-advocacy skills also influence whether or not an individual discloses to others (Lindsay et al., 2018). Overall, there is evidence that individuals with invisible disabilities prefer not to disclose unless necessary for obtaining academic or economic support (Moriña, 2017; Venville et al., 2014b). Interestingly, post-secondary support staff and instructors feel that student disclosure is beneficial to student retention and degree completion and expressed desire for more students to disclose, but stated they would not disclose similar circumstances to their own employer (Venville et al., 2014a).

Beyond the social circumstances and marginalization that accompanies being a student with mental health challenges, the nature of mental distress itself can impact the student experience. Importantly, mental distress is unique in that it typically has a cyclical nature and the impact of disability on academics fluctuates somewhat unpredictably over time (Kupferman, 2014; Mullins & Preyde, 2013). The impact of mental distress experiences on higher education includes both distress experiences and responses to medication, such as exhaustion, low mood, concentration, focus, motivation, memory, decision-making, organizational skills, and social withdrawal (Hartrey et al., 2017; Knis-Matthews et al., 2007; Markoulakis & Kirsh, 2013; Megivern et al., 2003; Salzer, 2012). These difficulties can make it challenging to attend class, participate, take notes, complete assignments, take exams, and maintain the expected level of productivity (Markoulakis & Kirsh, 2013).

Finally, as with all students, students with mental health challenges report a range of other life stressors that impact their ability to persist in post-secondary education. Financial stress is commonly reported among this group, including costs of treatment and medication, and household and educational expenses (Markoulakis & Kirsh, 2013). Conflictual social relationships are also commonly reported (Hartley, 2010; Megivern et al., 2003). Other reported stressors relate to family life, work, and general health concerns (Markoulakis & Kirsh, 2013). Notably, the transition to higher education itself can be stressful, and students at times place high expectations on themselves for academic and social performance that can be ongoing sources of stress (Wigginton, 2017).

#### Strengths and Supports for Students with Mental Health Challenges in Higher Education

There is evidence of both personal and structural strengths and supports for individuals with mental health challenges in higher education. It is important to consider this literature as it

suggests potential avenues for improvement of the current status quo. These involve individual attributes, informal supports, and formal supports and programs.

Some individual attributes that support success for students with mental health challenges in higher education have been identified. Importantly, the research summarized here tends to adhere to traditional ideas of what a "good" student is (e.g., self-managing, adaptable, adherent to treatment), and thus holds assumptions of individual responsibility and that adaptability to the status quo is equivalent to success that are inconsistent with the current project. Briefly, this literature finds that students who use active coping, effectively manage time, maintain discipline, do not take on too many responsibilities, and manage their medication and mental illness on their own are better suited to success in higher education (Hartley, 2010; Kain et al., 2019; Kranke et al., 2013; Lindsay et al., 2018). Whereas these results may indicate some potential sources of personal strength, they should be interpreted with caution as they also adhere to neoliberal, individualistic ideas and do not account for how social context and individual preferences may shape student access to various personal strengths. However, a brief discussion of personal attributes is important in order to acknowledge that, although structures can be altered to support student success, success is also the result of immense amounts of personal effort, skill, and ability that should not be erased or discounted.

There are factors within one's social context that influence success in higher education. Generally, support systems contribute to school success (Knis-Matthews et al., 2007). Of course, there would be variety in what form of social support students find helpful based on their own unique histories and preferences. There is evidence that families can be source of support by engaging in behaviors such as encouraging persistence, routinely checking in, providing practical support, and communicating support and trust in the student's decisions (Wigginton, 2017). Peer

relationships are also crucial, as peers can support fellow students in learning more about university, sharing opinions and developing worldviews, providing social support, supporting time and stress management, and supporting disclosure to others (Hartley, 2010). Thus, informal social supports can be helpful in bolstering student engagement in higher education.

Disability services and academic support are also essential to students with mental health challenges' engagement and inclusion in post-secondary education. There is much evidence in support of the importance of adequate disability support services for academic support, receiving accommodations, and providing information about rights (Hartrey et al., 2017; Lindsay et al., 2018; Magnus & Tøssebro, 2014). These systems are more effective when there is continuity of relationships and students are able to stay connected during periods of illness and hospitalization (Hartrey et al., 2017). Various supportive individuals also need to be well-connected to each other, so that support staff have the opportunity to explain to instructors how best to support students (Fossey et al., 2017). Having designated spaces for individuals with disabilities, such as a Library Centre, can provide spaces of acceptance, community, and safety (Mullins & Preyde, 2013). In terms of accommodations, faculty and students typically feel that extended deadlines, extra time to complete exams, and separate testing locations are helpful for students with mental health challenges (Brockelman, 2011; Brockelman & Scheyett, 2015; Kupferman, 2014). Faculty often report willingness to receive information from campus "experts" (i.e., disability support staff) on how to best support students (Brockelman & Scheyett, 2015; Venville et al., 2014a). While encouraging, this finding should be interpreted in light of ongoing concerns about "psy" professional dominance and accompanying epistemic injustice, as it suggests ongoing attitudes that professionals should be deferred to when interacting with and supporting individuals with mental health challenges, perhaps even above hearing from the student themselves.

Relationships with instructors and academic assistance from faculty are also important (Hartrey et al., 2017). Faculty with personal experience with mental distress are more likely to be supportive and positive in working with students who disclose mental illness (McAuliffe et al., 2012). Students also report desires for support that differ from faculty or disability support staff, including assistance developing natural supports, preparation for employment, and supporting independent living, suggesting potential areas for growth for these services and relationships (Kupferman, 2014).

# Structural Stigma in Higher Education

Structural stigma can be discussed both as shortcomings of existing services (e.g., insufficient availability of mental health services), and broader structural factors that underlie the existence of such shortcomings (e.g., underfunding of public mental health services). Much, if not all, of the research in this area focuses on structural barriers as shortcomings of existing services, as opposed to exploring what barriers may underlie these shortcomings. Thus, structural stigma will mostly be discussed in this way, with some theorizing where relevant on broader structural factors that lead to the existence and persistence of these barriers. Presently, structural stigma for people with mental health challenges in higher education occurs in several areas: 1) accommodation challenges, 2) lack of accessible information, 3) limitations to available mental health services, 4) financial, 5) structure of learning, 6) lack of support for alternative trajectories, and 7) lack of privacy and increased surveillance. These challenges may be different or exacerbated based on overlapping identities, as there is both inequitable access to education in Canada for individuals with mental health challenges, but also for individuals from low-income families, first-generation post-secondary students, immigrant and racial/ethnic minority individuals, individuals who grew up in rural areas, and individuals of Indigenous ancestry

(Michalski et al., 2017). Many of the individual problems and challenges reported in the above sections are indicative of greater structural barriers.

First, there are several issues with traditionally provided "accommodations" and student ability to access them, including: 1) barriers to self-advocating for accommodations, 2) practical, time-based, and financial challenges, 3) disclosure as a prerequisite for accessing accommodations, 4) inconsistent implementation and limited utility of accommodations. Before addressing specifically how these barriers operate within university settings, it is worth noting that these barriers exist due to overarching barriers of a lack of accessibility within higher education, and reliance on professional practices to judge disability. First, higher education largely does not ascribe importance to fostering accessibility for all in the first place, thus requiring an ongoing system to attempt to accommodate individuals on a case-by-case basis (Dolmage, 2017). The perpetuation of this system continues to construct disability as less than, and inhibits re-examination and potential shifts in pedagogy, and thus individuals with any type of disability must prove their disability and be assigned accommodations to make university more accessible for that particular individual, as opposed to changing learning and teaching in university to have accessibility built in (Dolmage, 2017). Second, the ongoing reliance on professional practices (i.e., assessment and diagnosis) to evaluate disability underlies these barriers. Much of the process of being awarded accommodation involves saying the correct things to the correct professionals at the correct time, creating its own set of barriers if one conceptualizes their experience differently, or if one, for various reasons, cannot gain access to the correct professionals. Such professional involvement re-creates historical dynamics rooted in eugenics where those in positions of power, bestowed by the university, control the lives of people with disabilities (Dolmage, 2017). This ongoing necessity for professionals to arbitrate

the process of who is worthy and unworthy of accommodations thus underlies many of the barriers which are seemingly inherent to the accommodation process.

The onus of deciding and engaging in the administrative processes necessary to receive accommodations is often placed solely on the student (Fossey et al., 2017). This model of self-advocacy is particularly troublesome for individuals with mental health challenges, as individuals tend to be diagnosed later in life (McEwan & Downie, 2013). This means that, although individuals with other forms of disability may be more aware of and able to advocate for longstanding needs to be met, individuals with mental health challenges do not have the benefit of experience to be able to do so, and thus available services may be less accessible to this group (McEwan & Downie, 2013).

There are also multiple challenges inherent in obtaining access to accommodations. The process of accommodation requires one prove that they are disabled "enough," which often involves formal diagnosis (Kruse & Oswal, 2018). This formal diagnosis can be time-consuming (i.e., if doctors or mental health professionals have long wait-lists) and expensive (i.e., if the student must pay for a formal assessment), which can make accommodations inaccessible to students despite legitimate need (Chambers et al., 2013; Giamos et al., 2017).

Accommodations often require some form of disclosure, which, as discussed, some students are uncomfortable doing as it may result in stigmatizing interactions with others, or may negatively influence future academic or career prospects if disclosed information becomes broadly accessible (Kruse & Oswal, 2018; Stein, 2013). Potential negative impacts of disclosure are not unfounded, as faculty are less likely to accept a student who discloses depression in an application than one who does not, despite rating both candidates equally suitable and equally likely to succeed (Zöld et al., 2020). In fact, Appleby and Appleby (2006) go so far as to

discourage disclosure in applications for graduate school as they suggest disclosure makes one seem "unable to function as a successful graduate student" (p. 23). Thus, students may find themselves in a double bind where they can choose whether to disclose their diagnosis in order to receive necessary and rightful supports, but this disclosure may in turn exclude them from future opportunities. In light of this, students may wait to disclose until in dire need of services, at which point student distress may make it challenging to effectively navigate services (Padron, 2006).

Finally, even if a student receives proper documentation and discloses their disability to university staff, accommodations are inconsistently implemented and frequently rely on the willingness of individual faculty, or involve students going through a complex and lengthy appeals process to ensure their academic needs are met (Fossey et al., 2017; Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013). Further, accommodations themselves can be ill-fitting, as they are often rigid and defined by the institution, and can be inflexible to meet individual student needs (Kruse & Oswal, 2018; Padron, 2006). Dolmage (2017) has highlighted that accommodations are designed first and foremost to meet legal standards and protect against claims of discrimination, and thus that it is more important for institutions to do something rather than the most helpful thing. For example, there is little research showing that extending the length of time people receive on tests is an effective accommodation, and thus, when such accommodations are applied in a blanket way to students with little follow-up, accommodations can be ill-fitting or unhelpful (Dolmage, 2017). Thus, existing institutional policies and practice are insensitive to the unique needs of individuals with mental health challenges, and at present are inconsistently implemented and rarely examined for efficacy.

Second, there is a lack of clear information on what resources are available to students. For example, students with invisible disabilities, including mental health challenges, report that their main barrier to accessing supportive funding is a lack of clarity regarding whether their disability clearly fits into any of the existing funding and support models (Chambers et al., 2013; Hartrey et al., 2017; McEwan & Downie, 2013). Similarly, students at times discuss that they do not seek support or accommodations for mental distress because they are not aware that their experience qualifies them for receiving support, do not know how to access support, or are not aware that academic and mental health support exists on campus (Fossey et al., 2017; Giamos et al., 2017; Hartrey et al., 2017; Lindsay et al., 2018; Megivern et al., 2003; O'Shea & Kaplan, 2018). Supportive structures and services implemented to reduce structural stigma can only be effective if they are reaching the population they intend to serve.

Third, there are limitations with the nature of mental health services provided through universities. These limitations are indicative of larger issues with mental health care in Canada, and oftentimes, internationally. In Canada and elsewhere, mental health care is underfunded, resulting in gaps in existing mental health services both in terms of types of services available and overall availability (Bartram, 2017; Cunningham, 2009; Latoo et al., 2022; Moroz et al., 2020). There is also a lack of funding to employ and train sufficient numbers of mental health professionals to meet service needs (Bartram & Chodos, 2018; Latoo et al., 2022; Moroz et al., 2020). In Canada, services are not covered by universal healthcare, and thus although some individuals may have some funding for mental health care through private insurance, it remains common for individuals to pay for mental health care themselves, resulting in financial barriers for many (Bartram, 2017). Although many argue for better funding and support for mental health in light of these statistics, it is also worth noting that these issues, and their accompanying

solutions, rest on assumptions of "psy" dominance: that mental health challenges require individual re-dress, and it is more highly trained professionals that are required to support such individual efforts at recovery from mental illness. Sarason (1974) warned against such approaches, arguing that the discrepancy between individuals requiring mental health support and trained professionals would always be "scandalously large." Thus, it is not only the more often discussed limitations to mental health funding and professionals that underlie barriers to mental health services, but also the narrow focus on improving individualized mental health services as opposed to broader community approaches to mental health that underlie barriers related to mental health services.

With this in mind, we can turn specifically to what types of barriers exist within university mental health services. Importantly, the bulk of services are focused at the individual level (e.g., accommodations, skill-building, growing confidence), and do not address structural barriers (Markoulakis & Kirsh, 2013; Venville et al., 2016). Available services to students in distress tend to promote a homogenizing view of distress through programs such as Mental Health First Aid or other 'mental health literacy' approaches, leaving little space for those with alternative views or experiences (de Bie, 2019). There are also implicit beliefs that services such as campus security should be involved in managing psychiatric crises, implying beliefs of dangerousness and unpredictability (Kupferman, 2014). This not only excludes students who do not adhere to these views of distress, but also can leave students feeling abandoned academically as they are "referred out" to health services without sufficient attention being paid to their further educational growth and development (de Bie, 2019). Further, traditional university counselling offered by universities is often not culturally relevant to Indigenous students, international

students or students from non-dominant cultural backgrounds (Giamos et al., 2017; Shankar et al., 2013).

Even when students do wish for traditional mental health services within the university setting, these services are often unavailable (e.g., long waitlists), inaccessible (e.g., restricted hours of operation), reactive to crises rather than preventative, and fail to adequately coordinate between services within and external to the university (Chang et al., 2020; Hartrey et al., 2017; Markoulakis & Kirsh, 2013). Students in the United States cite barriers to help-seeking including lack of knowledge, stigma, no transportation to services, and no time to access services (Marsh & Wilcoxon, 2015). Further, professionals in these services may hold their own stigmatizing beliefs, and may encourage students to withdraw from post-secondary education (Padron, 2006). There is ample literature on structural stigma which exists in healthcare contexts for individuals with mental health challenges, and includes inequitable access to care, poor quality of care, and stigmatizing interactions while receiving healthcare (Livingston, 2020). It is plausible that healthcare contexts within university settings mirror other healthcare contexts, and thus the range of structural stigma encountered within healthcare settings may extend to seeking physical and mental health care within post-secondary health centers. Thus, there is evidence that existing support services are lacking in variety, accessibility, and quality, and that students accessing these services may encounter further stigma through their interactions with providers.

Fourth, students with mental health challenges may struggle with finances and accumulating debt from post-secondary education (Hartley, 2010; Megivern et al., 2003). This may be exacerbated by challenges accessing financial support when pursuing non-traditional pathways through higher education, such as being a part-time student for longer than four years or leaving and returning to school (Wigginton, 2017). In the United States there is evidence that

financial costs associated with treatment are the most significant barrier to help-seeking among post-secondary students, potentially leaving students to choose between accessing the care they desire and continuing with their education (Marsh & Wilcoxon, 2015). Such financial barriers can be exacerbated in multiple cases such as, for example, when students are from a low-income background (Hartley, 2010; Megivern et al., 2003), and for visible minority and Indigenous students, where existing funding structures are often inadequate (Shankar et al., 2013). Thus, unique financial barriers to higher education and a lack of supports that consider this inequity is another form of structural stigma in higher education.

Fifth, the structure of learning and the power of instructors creates structural barriers. Overall, post-secondary institutions tend to be set up for "one type of learner," and students may have to endure a variety of ill-suited experiences such as loud and busy lecture halls, timed tests, and strict timelines and definitions of appropriate classroom participation that may exclude individuals who struggle to participate as this type of learner (Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013). Typically, the onus is on the individual student to adapt to this form of learning (Venville et al., 2014a). Further, the competitive culture of higher education may cause the skeptical interactions students seeking accommodation experience with instructors and peers where it is believed that those with invisible disabilities are exaggerating or "faking" in order to receive unfair advantages (Hartley, 2010; Kruse & Oswal, 2018).

Presently, feelings of success and inclusion often depend on individual instructors, rather than on higher level institutional inclusion (Stein, 2014). There are further structural barriers to faculty supporting students, as faculty report a lack of time and skill to spend with students experiencing distress (Hartrey et al., 2017). Thus, students experiencing distress can have a variety of experiences where some instructors are knowledgeable of disability services and are

willing to collaborate with students, and others lack appropriate knowledge and can have highly negative interactions with students, such as skepticism about the student's disability (O'Shea & Kaplan, 2018; Reid & Poole, 2013; Stein, 2014). Thus, there is a lack of systemic supports in place to ensure broader inclusion and accessibility for students with mental health challenges, and instead students may navigate multiple complex and stressful situations depending on the type of classroom and instructor they encounter.

Sixth, there is evidence that students with mental health challenges may benefit from an alternative trajectory of degree completion than the typical four-year, full-time student. Such trajectories are often ill-supported by institutions. Specifically, there is evidence that leaving and returning to school is an important part of degree completion for students with mental health challenges (Markoulakis & Kirsh, 2013; McEwan & Downie, 2013; Megivern et al., 2003; Wigginton, 2017). These varied trajectories of student degree completion are often ill-supported by institutions, which offer little practical or social support for returning students, or students who do not transition directly from high school (McEwan & Downie, 2013; Wigginton, 2017). In fact, leaving and returning to school often results in large amounts of paperwork and administrative responsibilities for the student, with little support to help them navigate this bureaucracy (Wigginton, 2017). Thus, the lack of support for students who do not follow a typical four-year degree trajectory without taking leave may disproportionately impact students who struggle with their mental health.

Finally, there is an overall lack of privacy and increased surveillance of students in mental distress, where students may be denied access to certain privileges (e.g., keys, after hours access), or may be subjected to intrusive advice or restrictions (Kruse & Oswal, 2018; Livingston, 2013). Importantly, the risks of stigma and surveillance are increased when one

either does not adhere to or does not benefit from traditional treatment modes (Kruse & Oswal, 2018). This aligns with the distributed power that occurs to attempt to bring individuals into alignment with existing mental health norms even by those who are not directly related to the mental health professions, such as university administrators and faculty (Roberts, 2005; Swerdfager, 2016). It is clear that there are many facets of typical post-secondary culture which, at best, result in inconsistent supports and attitudes toward individuals with mental health challenges, and at worst, exclude such individuals from important opportunities for development.

## **Researcher Positionality**

A key assumption within this dissertation is that research is a fundamentally subjective process: the products of research are always filtered through the lenses and experiences of the researchers themselves. As such, it is essential that I am transparent about who I am as I undertake this research project. I started this research project identifying as someone who did not have the lived experience of mental health challenges I was researching, however I have felt this position become complicated throughout this project. It remains true that I have not been exposed to several of the most pronounced power imbalances that exist for those with mental illness (e.g., diagnosis, hospitalization), and that I do not identify as someone who is Mad or has a mental illness.

Although I initially felt that I was removed and did not have the experiences of barriers associated with mental health challenges that I would be researching, I no longer feel this is the case for two reasons. The first reason is simply, life. In the process of writing this dissertation, several stressful life events occurred and my own mental health suffered to the degree where, for the first time in my educational career, I did not feel it was possible to "power through" or "press on." I needed to ask for accommodation, to disclose to others that I was struggling, to slow

down, to weigh the options of attempting to continue as normal with withdrawing from classes and taking a formal leave. Second, I was also surprised to find, through relationships with my research assistants and with participants, that several of my experiences, especially within my undergraduate degree, mirrored theirs. Thus, those experiences that I had during my earlier life which I had long ago assigned the meaning of my own individual failings or idiosyncratic needs arose for re-thinking and re-examination during this research undertaking both as related to my own mental health and its intersection with university structures. In this way, although I set out with the aim to do research in such a way that would collectivize experience and thus re-shape the meaning of experience for others, I was startled to find that this re-shaping of experience happened for me, as well.

Further, through this research we have discussed within our research team and with our participants the downsides of having essentialist views of who "counts" and who "does not count" as having experience with mental health challenges, which has engendered in me a more fluid and evolving view of my identity in this regard. Thus, whereas my position upon starting this work was that I am separate from the group I am researching, my own views and experiences have shifted in such a way that no longer allows me to conceptualize myself (or others) as having a static identity that is "in" or "out." Despite these shifts, there are still many barriers and experiences discussed in this study which I have not personally experienced, and thus I recognize an ongoing gap between my own experience and that which I am researching, in which there remains an ongoing risk for distortion and misinterpretation of the knowledge produced (Glasby & Beresford, 2006). Throughout this project, I have aimed to be intentional in noticing my reactions to certain individuals and ideas, and question how my inclusion, dismissal, and understanding of ideas is limited by my experience.

Another way in which I interact with mental health discourse is as a graduate student in clinical psychology. In this role, I have benefited from the perpetuation of ideologies that diagnose, separate, and individualize problems associated with mental distress. I have years and years of education, study, and writing on the status quo: on diagnostic labels, assessment and treatment, and have felt the various complexities of engaging or disengaging in these systems. I have felt, especially at the start of this project, the discrepancies between how I speak and conceptualize issues as a professional training in clinical psychology versus how they are spoken about and viewed by individuals with lived experience, and at many times still feel myself slipping back and forth between these two worlds. I also have grappled with the extent to which I have and do and will benefit greatly from my involvement in this discipline, both financially and in terms of personal fulfillment. I am completing this dissertation itself not only with the aim of addressing barriers to higher education for individuals who have experienced distress, but also so that I can be awarded my PhD, which will grant me even greater power, status, and access to resources.

There are other aspects of my identity that have protected me from experiencing certain barriers to education and access to services. I am from a White, upper middle-class family with Mennonite heritage. Both my parents completed university education, and thus have been able to advise me from experience about how to navigate university systems. This background as a White, upper-middle class woman of settler heritage has also led me to have a sense of belonging in university in the sense that such spaces were and are created for people of my background.

As a student, I have felt strain in balancing my needs and goals to complete a product in a timely manner that is well thought of by the academic world with creating something that is meaningful to community and makes a tangible impact. In this regard, I have struggled in my

role as a student, where I feel well-versed in how to deliver academic products, but highly insecure and uncertain about how to go about creating meaningful change in systems which I feel I am only beginning to grasp. Here, discussions with those who work on such change and ongoing engagement with my research team have held me accountable and encouraged me to see the value in moving forward despite not seeing the path.

A tension that my roles and identities have created throughout this project and will continue going forward is that my position of power affords me the possibility of not continuing to engage in this work should I choose not to. I could still choose at any time to stop thinking about the power and responsibility of my role and of the greater mental health systems I participate in, and with this choice I could experience very little negative consequence, and perhaps experience personal and professional gain. This is in stark contrast to those who have lived this experience, who have no choice but to do their best to understand and navigate complex and oppressive systems, at times as a matter of survival. At the same time, my position as a student in clinical psychology has allowed me to work in various settings designed to assist individuals experiencing mental distress. This has given me the opportunity to learn directly not only about the individual-level approaches used within "psy" disciplines to address distress, but also to learn about the systems and associated barriers in which such treatments take place. Thus, grappling with the plentiful power that I have, how to use it well, and how to consider what I do not in a vacuum, but within the web of other responsibilities and priorities I have in life has been essential to this research process. The answers to tensions and conflicting priorities that arise have rarely been simple (see Chapter 4: "Reflections on the Power and Pitfalls of Participatory Practices on Our Research Team").

#### **Participatory Methods**

It is clear that there are ample structural barriers to higher education for individuals with mental health challenges that are in need of being addressed. As a person who lacks lived experience in certain areas at the intersection of mental health and university, and a person who has received ample training to be a psy professional, centering my own perspectives and ideas in this research and dictating solutions would run a high risk of re-creating the very same professional/patient hierarchies that are the root of so many of the structural injustices that are experienced by individuals with mental health challenges. Thus, I used participatory practices within this dissertation. Since I made decisions about study design and research questions without formal involvement of individuals with lived experience, this project cannot be considered community-based participatory research or any fully participatory method. However, I do aim to adhere to participatory principles, and thus review literature on participatory methods in order to inform positive participatory practices within this dissertation.

Participatory research does not refer to any specific research methods, but to research endeavours that value the engagement of individuals with relevant lived experience within the research process (Bergold & Thomas, 2012). These methods tend to be applied especially with communities or populations who have been historically marginalized (Bergold & Thomas, 2012). In this project, I aim to align most closely with the tradition of participatory action research (PAR), though, as mentioned, this project cannot be fully classified as participatory action research. PAR is unique in its specific focus not only on involving individuals with lived experience, but also on creating change and improvements for the people involved in the research (Lake & Wendland, 2018; Rempfer & Knott, 2002). Thus, rather than being driven by a particular theory or method, PAR is an approach oriented to social change (Lake & Wendland,

2018). Regardless of specific research method, PAR is defined by collaboration and by goals of social transformation, with attention paid to unjust social structures (Lake & Wendland, 2018). Within PAR, there is also a focus on challenging existing power dynamics of who the "expert" is (Lake & Wendland, 2018; Rempfer & Knott, 2002). In this way, the act of performing PAR itself also has the potential to be transformative, as it places historically marginalized groups in positions of power to design and implement research projects, as well as to disseminate information, thus challenging existing hierarchies (Lake & Wendland, 2018; Rempfer & Knott, 2002).

There are a range of strengths embedded within participatory methods. First, power is not static within professional and community researcher relationships. Whereas professional researchers may have more power within the academic setting, community researchers may have more power within the community, acting as "bridges" to the community, and potentially having access to unique knowledge and insights from the community (McCartan et al., 2012; Muhammad et al., 2015). There is also the potential for mutual benefit and sharing of knowledge, as community researchers may gain more traditional "research" knowledge over time, and professional researchers may gain more community-based knowledge over time (McCartan et al., 2012). It has also been noted that the inclusion of the community leads to multiple benefits, including greater community commitment to the research project, a higher standard of accountability for researchers (i.e., to community partners as opposed to solely traditional sources such as granting agencies and journal editors), and improved abilities at logistical problem solving due to involvement of both those with research and community knowledge within a project (Lake & Wendland, 2018; McCartan et al., 2012; Rempfer & Knott, 2002).

Importantly, simply declaring a project as PAR is insufficient to achieve goals of true participation, change, and sharing of power. In order to become aware of potential pitfalls and recommendations within participatory research, I reviewed literature focusing on challenges to participatory research, as well as recommendations for addressing challenges within participatory research. I reviewed materials from a variety of participatory approaches, including participatory action research, community-based participatory research, and patient engagement.

## Challenges to Participatory Research

There are a number of challenges to doing participatory research, including: 1) barriers to making research truly "participatory," 2) unequal power, 3) risks of harm, and 4) concerns about the institutionalization of participatory methods.

Several challenges to implementing truly "participatory" research arise within institutional structures. Although participatory researchers make conscious efforts to involve community members within research, there are often barriers to participation including financial barriers, language barriers, community members being overwhelmed or intimidated, or community members burning out from being repeatedly invited to participate in research projects (Reason, Bradbury, Grant, Nelson, & Mitchell, 2011). There may always be "invisible" community members who are either excluded or do not receive information about the project, and these "invisible" members are often those who are most disenfranchised, challenging assumptions that participatory findings are inherently representative of community interests (Bergold & Thomas, 2012; Rempfer & Knott, 2002). Further, when opportunities for involvement in participatory research are limited, participation may become a privilege or a competition among community members (Bergold & Thomas, 2012). Even if adequate participation from a community is achieved, simply delivering an opportunity for participation is

not sufficient for ensuring that participants feel safe to speak, or that their voices will be meaningfully taken into consideration (Strumińska-Kutra, 2016). Participatory research at times assumes that participants will be willing to disclose personal experiences and opinions that are typically saved for trusted friends within an institutional setting (Bergold & Thomas, 2012). This is a dubious assumption, as marginalized groups can create "hidden transcripts," in which true thoughts and emotions are hidden in favour of espousing dominant norms and beliefs in order to protect community values from outside researchers (Muhammad et al., 2015). Thus, research that aims to be participatory should attempt both to reach many individuals within the community, especially those who may be alienated or disenfranchised, and should spend ample time building trust in order to create a space where true opinions can be expressed and respected. However, even with these efforts, researchers must acknowledge that full community participation, representation, and comfort is unlikely (or impossible) to achieve, and thus to qualify results as limited in the extent to which they truly represent a particular community or group of persons.

Further, although the ideals of participatory research are to have co-researchers with lived experience involved throughout the research design, data collection, analysis, and knowledge translation phases, traditional research infrastructure makes this challenging to achieve in practice. Specifically, acquiring funding to engage with communities is often the first step towards a participatory research endeavour, and acquiring such funding often rests upon first proposing a research study and design without having the time and resources to adequately engage with the community (Bergold & Thomas, 2012; McCartan et al., 2012). As McCartan and colleagues (2012) state, "Participatory projects only become participatory once the study design has been ratified by those providing the money." Thus, hierarchies may exist within participatory projects from the outset as academic researchers have to be accountable both to

funding bodies and to community partnerships, and have often made decisions without community input.

Though participatory methods seek to equalize power, there is ample potential for remaining hierarchical power structures. Overall, it has been concluded that power relationships can be reduced, but not erased, through participatory methods (Reason et al., 2011). This is because both the status and position professional researchers hold is often more powerful than those of community members they seek to partner with, and because researchers also exercise power by virtue of working in an environment that is familiar to them within an area of their expertise (McCartan et al., 2012; Muhammad et al., 2015). Community partners will likely not have research experience to the same extent that professional researchers do (McCartan et al., 2012). Further, there can be reproduction of power differentials based on characteristics such as gender, racial/ethnic background, educational differences, and socioeconomic inequalities within research teams (Muhammad et al., 2015).

There is an inherent tension in trying to conduct equalizing research within cultures and institutions that are undeniably hierarchical, such as a university (Strumińska-Kutra, 2016). In this sense, participatory research may be particularly susceptible to lack of awareness in the negotiation of power, as it may amplify local knowledge over incorporating critical perspectives that acknowledge the inherent power differentials within cultural, institutional, and social environments within which the research is taking place (Strumińska-Kutra, 2016). Thus, in this project, it is key to acknowledge that the research being undertaken seeks to collaborate with individuals with mental health challenges, but does so in a culture that is currently dominated by the medical model and narratives of "wellness" that prize the knowledge of professionals. This is especially important to acknowledge as I am a mental health professional in training. Thus, there

are larger institutional and societal forces of power that influence relationships within the research team, relationships with participants, and everyone's access to non-dominant narratives of mental illness. For example, it was found in previous mental health research with individuals with mental health challenges that participants felt pressure to "speak wellness" due to dominant narratives of recovery (Pascal & Sagan, 2018). Thus, balancing both local knowledge and attention to how larger power structures may influence the research process and findings is essential.

There are unique potentials for harm within participatory research. First, it has been suggested that most participatory research benefits the researcher more than the community (Reason et al., 2011). This may be especially pertinent within forms of participatory research that imply or promise "change," such as PAR, as researchers may be focused on more comprehensive social change, whereas communities may want and need smaller, more urgent local change (Reason et al., 2011). A related ongoing issue is what Lucy Costa refers to as the "saturation of data" within participatory research, where ample information about desired systemic change is already available, but participatory research projects often focus on further consultation for "what is needed" instead of advocating for or implementing changes that are already known to be desired (Johannsen & Nicholas, 2020). Thus, communities may dedicate ample time to consulting with researchers without researchers committing to follow through with tangible benefit or change.

There are also unique ethical concerns within participatory research, including the reduced privacy of participants, and the potential for conflict and alienation to arise when bringing community members with different roles and opinions together (Lake & Wendland, 2018). Institutional ethics boards may not be sensitive to the same risks of harm as community

members, and thus may be inadequate to assess risks (Lake & Wendland, 2018). Further, a particular arrogance may arise within participatory researchers where researchers may view their projects as infallible simply by virtue of being participatory (Lake & Wendland, 2018). This may lead to inadequate attention to potential risks, including homogenization of community perspectives, denial of the potential for ethical violations or exploitative practices, inadequate attention to those involved experiencing emotional challenges, disputes over authorship and ownership of data, and potential social and political consequences for participants (Lake & Wendland, 2018). Thus, it is essential to be mindful that participatory methods are not inherently more virtuous, and that the need for humility, reflection, and third party oversight remains essential (Lake & Wendland, 2018; Rempfer & Knott, 2002).

Finally, there are concerns about the institutionalization of participatory methods. Participatory methods occupy a challenging position in current practice, as they are caught in between grassroots social activism and dominant institutional acceptance, and thus are critiqued from both sides. First, it has been noted that whereas "participation" originally was an orientation towards radical transformation outside of dominant systems, it has become "modified, sanitized, and depoliticized" (Leal, 2007, p. 543) as it has gained acceptance within traditional academic structures (Lake & Wendland, 2018). Thus, institutional participatory research may be used to establish local problems, but apply solutions that mirror dominant interests, goals, and processes (Leal, 2007; Rahnema, 1990). Leal (2007) writes that participatory research must be repoliticized, and the only way this can be done is by the disenfranchised "seizing" power from the powerful, and cannot be achieved by the powerful "handing" power to the powerless, as is presently done in participatory research. On the flip side, participatory methods are also not fully accepted within dominant institutions. Participatory methods go against dominant notions of

"legitimacy" due to a lack of separation between facts and values, and between knowledge production and knowledge implementation (Strumińska-Kutra, 2016). Participatory methods also aim to prioritize different goals (e.g., empowerment, collective action) than traditional academic markers of scholarly impact and economic gain (Lake & Wendland, 2018). Thus, participatory methods currently walk a middle path between grassroots social transformation and traditional academic research, with challenges arising from both ends of the spectrum.

#### Practice Recommendations

A number of important recommendations for best practices within participatory research have been made within the domains of: 1) composition of the research team 2) reflexivity, 3) sharing power, 4) transparency, and 5) being deliberate about how community team members are benefited by participation.

By definition, successful participatory research must meaningfully involve, both within the research team and as participants, individuals with the particular background or lived experience of interest. Involving community members on the research team whose identities intersect with the community of interest is central to overcoming many of the challenges outlined above (e.g., trust and open sharing, unequal power, mitigating risks of harm; Muhammad et al., 2015). For those team members whose identities do not intersect with the community of interest, humility is essential (Muhammad et al., 2015). However, it is not enough to simply involve coresearchers, but to also share power with these researchers. Although there is no general agreement about a method to reduce power differentials, it is generally acknowledged both that power differentials cannot be fully ameliorated, and that there are several different practices one can engage in to address power (Lake & Wendland, 2018).

First, researchers must practice their own reflexivity. This self-reflexivity begins with the assumption that research is personal, and that the researchers' professional, political and social selves are inextricably linked to the research process and findings (Lake & Wendland, 2018). Reflexivity includes reflecting on one's identity, experiences, and positionality, and on institutional, structural, and dominant forces within both the researcher and the researched as the project unfolds (Bergold & Thomas, 2012; Lake & Wendland, 2018; Muhammad et al., 2015; Reason et al., 2011). These reflections should include an explicit focus on how the researcher's experiences and identity relate to systems of power and oppression (Lake & Wendland, 2018). Being aware of such things allows the research team to embrace inevitable tensions in participatory work (Luttrell, 2000). This reflexivity can be exercised through research diaries, workshops, and supervision, and may involve reflecting as a research team (Bergold & Thomas, 2012). There must also be reflection regarding the research methods: Why are we asking some questions and not others? Who is defining the research process? Whose voices are privileged in presenting the findings? How is power embedded within the construction of knowledge in this area? What is the impact of viewing the phenomena in this specific way as opposed to others? Why are we involving some people and not others? (Muhammad et al., 2015; Kneebone & Wadsworth, 1998). Such questions acknowledge the active researcher, with their own subjectivities and opinions, within the research process, and thus offer important context for how a project develops and unfolds.

The second set of strategies for sharing power and building successful research partnerships involves meaningful discussion of the contributions of different team members, and being explicit about where and why certain team members have more control than others.

Overall, one must be aware of whether research partners have the same decision-making rights

and responsibilities as academic researchers within a project (Bergold & Thomas, 2012). If they do not, the research is not participatory (Bergold & Thomas, 2012). Arnstein's (1969) ladder of citizen participation is a commonly used tool to determine to what extent academic researchers are sharing or yielding power to research partners, and contains various levels that describe nonparticipation (e.g., therapy, manipulation), tokenism (e.g., consultation, informing), and citizen control (e.g., delegation power, partnership) (Lake & Wendland, 2018). More recently, Wong and colleagues (2010) propose a model of sharing power within participatory research with youth. They refer to "pluralistic participation" as a reciprocal relationship of power sharing between youth and adults. Though different projects may require different balances of power, pluralistic participation acknowledges that both community research team members and researchers have strengths, and that these strengths will be more useful for different decisions and processes, and thus that every decision and activity may not require equal participation (Wong, Zimmerman, & Parker, 2010). They posit that co-researchers with lived experience may contribute creativity, experience, and willingness to try new ideas, whereas academic researchers may contribute knowledge of research and evaluation practices, background knowledge about community history and already established knowledge, and knowledge about practical planning and timelines (Wong et al., 2010). Thus, in this view, being explicit about which parties will bring the most appropriate knowledge and skills to different decisions is important (Wong et al., 2010). This involves meaningful exploration and discussion of co-researcher and academic researchers' skill sets and strengths and weaknesses (Muhammad et al., 2015).

Beyond solely capitalizing on the strengths of different members, it is also important to share knowledge within teams so that all team members become well-versed in various forms of knowledge. This may occur through "up, down, and peer mentorship," which sets meaningful

contribution from members in different positions as the norm (Muhammad et al., 2015). Successful sharing of knowledge involves "mutual curiosity" about the knowledge and experience of members in different positions (Bergold & Thomas, 2012). For researchers, this involves both sharing of knowledge of research methods and process, and sharing with coresearchers and participants already available knowledge (Bergold & Thomas, 2012; Johannsen & Nicholas, 2020). As Lucy Costa states, "you have to do the real engagement work, which is make information accessible, make it relevant to people's lives. If they're going to be informing a process like the lack of housing, you don't ask people how they feel about the lack of housing, you inform them: 'This is what we know about the housing situation, this is what we've heard about it, based on that, what might be a useful process of conversation and dialogue." (Johannsen & Nicholas, 2020; 19:05). As information is shared, power may shift as coresearchers or community members become more involved and demand more control of the research process (McCartan et al., 2012). This shifting of power will likely result in resistance from researchers, and is a key shift for researchers to be aware of and reflective on (McCartan et al., 2012).

Within participatory research, transparency within the research team must be prioritized. The most important precursor of transparency is simply time: regular team meetings to maintain open dialogue, time for every member to share their opinions, and time to discuss inherent tensions and power within participatory work (Muhammad et al., 2015; Reason et al., 2011). From academic researchers, this involves honesty about required outputs (e.g., a dissertation, published articles), timelines, and the institutions and groups to which academic researchers are accountable (e.g., funders, supervisory committees, university; Bergold & Thomas, 2012; Reason et al., 2011). This also involves transparency that change is a slow process, and ongoing

discussion of how decisions will be made within the project, including who will be involved, what their rights are, and when they will be given opportunities to participate in decision-making (Bergold & Thomas, 2012; Reason et al., 2011). In all processes, academic researchers should also avoid high level academic language (McCartan et al., 2012). Essentially, researchers must also convey that the research team need not be a conflict-free space, but a space to collaboratively decide how and when to discuss conflicts that will inevitably arise (Bergold & Thomas, 2012).

Finally, discussing and being explicit about benefits to co-researchers is essential. Having adequate pay for co-researchers is necessary, as it not only recognizes their value, but also can broaden the accessibility to others who may not be financially able to participate otherwise (Bergold & Thomas, 2012; McCartan et al., 2012). Desired benefits of co-researchers should also be discussed and committed to, and may include resume enhancement, preparation for the labour market, involvement in academic publications or conference travel, and the opportunity to make a difference (McCartan et al., 2012; Muhammad et al., 2015).

### **Dissertation Setting: University of Victoria**

The University of Victoria is a mid-sized Canadian university situated on southern Vancouver Island. British Columbia does not have accessibility legislation (Cheang, 2022). This is unusual as, for example, the Ontario Human Rights Commission has a specific policy entitled "Policy on Accessible Education for Students with Disabilities," (Ontario Human Rights Commission, n.d.) whereas no such specific policy exists at the provincial level in British Columbia. The BC Human Rights Code does specify that a person may not be discriminated against in "accommodation, service, and facility" due to a disability, which entails certain responsibilities within a university (BC Human Rights Code, n.d.). Because of this, individual

universities create their own policies based on guidance from the Canadian Charter of Rights and Freedoms, and the British Columbia Human Rights Code. The University of Victoria has a policy entitled "Academic Accommodation and Access for Students with Disabilities," (University of Victoria, 2017) which outlines the rights, responsibilities, and key definitions relating to academic accommodation at the University of Victoria. The policy requires that students with disabilities self-identify to the Centre for Accessible Learning with documentation of their disability. If they are approved, "reasonable accommodation" is to be provided to them, defined as "an individualized modification of environments, materials or requirements which provides the student with an alternative means of meeting essential course or program requirements" (University of Victoria, 2017; p. 5). A list of potential accommodations is provided in the document, and includes course-based academic accommodations (e.g., receiving copies of course notes, audio recorded lectures, or assignment substitution), exam-based accommodations (e.g., receiving extra time on exams, distraction-reduced space for writing exams, use of a word processor or spell check), and accommodation related to administrative processes, such as for early registration, alternative texts or materials, or reduced course loads. The policy outlines that instructors who fail to provide reasonable accommodation to students registered with CAL are at risk of receiving a human rights complaint (University of Victoria, 2017).

Many of the services that are formally available to students through the University are within the University of Victoria's division of Student Affairs, which includes Health Services, Counselling Services, Multifaith Services, Office of Student Life, Centre for Accessible Learning, Academic Advising, and International Student Services (see University of Victoria Student Affairs, 2022, for an organizational flow chart). At Health Services, students can access

family doctors, nurses, mental health nursing, and psychiatry (University of Victoria, n.d.[a]). Counselling Services includes both same-day appointments, brief counselling services, and group counselling provided by counsellors and psychologists (University of Victoria, n.d.[b]). Multifaith Services includes spiritual care providers, predominantly from Christian traditions with representation of Buddhist, Muslim, Jewish, and Baha'i traditions (University of Victoria, n.d.[c]). This center provides both individual meetings and group programming, both associated with specific spiritual traditions and those which are intended to cater to individuals regardless of spiritual background (e.g., non-secular meditation; University of Victoria, n.d.[c]). The Office of Student Life is a broad department which provides both one-on-one case management services to university students experiencing complex mental health challenges and life situations, and broader initiatives aimed at supporting student leadership, student mental health, and prevention of sexualized violence (University of Victoria, n.d.[d]). Clubs and course unions, some of which focus on mental health specifically, are also housed within the Office of Student Life (University of Victoria, n.d.[d]). The Center for Accessible Learning supports students via academic accommodations for students with neurodevelopmental, mental health, chronic health, and physical disabilities (University of Victoria, n.d.[e]). Academic Advising supports students in defining and pursuing specific career and academic goals, and in navigating issues such as transferring credits and resuming studies after absence (University of Victoria, n.d.[f]). The International Centre for Students provides supports specifically for international students, including both academic advising and social programs intended to increase connection (University of Victoria, n.d.[g]). There are also practical services available to students through the Office of the Registrar including requests for academic concession and fee reduction appeals

that can be used in relation to disruptions in academics related to mental health challenges (University of Victoria, n.d.[h]).

There are several other formal resources available through UVic. The Office of the Ombudsperson is a resource independent of UVic which supports students in resolving disputes by supporting students to navigate appeals processes and complaints (Office of the Ombudsperson, University of Victoria, 2020). The Equity and Human Rights office offers support for human rights violations occurring within UVic, including sexualized violence, harassment, and discrimination (University of Victoria, n.d.[i]). Their focus is primarily on supporting UVic employees through training and resources to adhere to non-discriminatory environments, but also includes support for students making complaints or reports of human rights violations (University of Victoria, n.d.[i]).

There are also services provided for students through the University of Victoria Students' Society (UVSS) and the Graduate Students' Society, which are student organizations on campus. Health and Dental plans for students are provided through these organizations, including varying amounts of financial support for mental health services (University of Victoria Graduate Students' Society, 2022a; University of Victoria Students' Society, 2020a). In 2022, this was \$700 per calendar year for mental health services for undergraduate students, and \$500 for graduate students. These amounts are restricted in terms of type of professional, and for some reimbursements additional medical documentation of therapeutic necessity is required. The UVSS in particular also contains a variety of student-led support services, social groups, and advocacy groups for students. The Peer Support Centre is an organization of student volunteers who offer emotional support and practical support navigating UVic services (University of Victoria Students' Society, 2020b). Throughout COVID-19, the Food Bank and Free Store has

offered free hampers of food and hygiene items to students (University of Victoria Students' Society, 2020c). Advocacy groups include services that provide social spaces and programming for students, as well as advocacy for the rights and safety of various student groups, and include the Native Students Union, the Gender Empowerment Centre, the Society for Students with a Disability, the Students of Colour Collective, and UVic Pride (University of Vicotria Students' Society, 2020d). Containing fewer formal organizations, the Graduate Students' Society advertises peer support, referrals, and advocacy (University of Victoria Graduate Students' Society, 2022b).

### **Summary and Current Study**

Within this chapter, I have outlined important historical and present-day context that has led to the marginalized position of individuals with mental health challenges, both in society more broadly and specifically in higher education settings. The consequences of "psy" dominance, including consequences for how we discuss and purportedly address stigma are central to this marginalization (Rimke, 2016; Tyler & Slater, 2018). Central challenges that lead to the persistence of marginalization includes the individualization of mental distress and a concurrent lack of attention to structural barriers to accessing basic rights such as housing, employment, education, and healthcare (Costa et al., 2012; Holland, 2018; Rimke, 2016). One mechanism by which attention remains on the individual and away from the structural is a lack of representation of persons with mental health challenges in positions of power to generate knowledge, as it has been noted that research originating from these individuals tends to have a more explicitly social justice perspective (Costa et al., 2012; Landry, 2017). My focus on higher education, then, is intended to begin to increase access to knowledge generation power for such individuals, so that future research not only about justice and action, but also about the culture,

history, art, and identity of mental illness and/or Madness, can proliferate (Jones & Brown, 2012). In line with this, I have reviewed the current knowledge base on experiences of higher education for individuals with mental health challenges, and have summarized what is known about structural barriers.

In this dissertation I am choosing to explicitly focus on understanding and addressing structural barriers to higher education for individuals with mental health challenges at the University of Victoria. The intent in utilizing the term structural *barriers* rather than *stigma* is to explore the individual-level felt experiences that result from higher level structural stigma. For example, a participant who indicates being impacted by long wait times for services is experiencing an outcome of structural stigma since scarcity of services is driven by a lack of prioritization of and funding for mental health services. Thus, structural stigma is explored through the lives of those impacted in their immediate experience, rather than through analysis of the formal policies, laws, and procedures that create structural stigma, which has been noted as the primary method for examining structural stigma (Livingston, 2021).

This project is limited to University of Victoria students as each university has unique structures and internal systems, and each university is also situated in larger communities that are characterized by various structural opportunities and constraints, and thus I feel the results will be more meaningful and actionable if a specific community is centered. Although some structural barriers for students with mental health challenges at university have been identified, to my knowledge very few studies to date have explicitly focused on identifying and prioritizing structural barriers that students with mental health challenges face, even fewer have done so with meaningful engagement of students with mental health challenges, and none have combined this with an action-oriented component. My hope, then, is that this research will fill both a research

and practical gap for individuals with mental health challenges. Thus, this dissertation is comprised of two studies: 1) an online survey aimed at identifying impactful structural barriers, and 2) a collaborative workshop to prioritize and discuss in further depth structural barriers and potential solutions. The first study serves as a pilot investigation of structural stigma at the University of Victoria to inform a more in-depth investigation of a particular area of structural stigma in Study 2. Overarching aims of this dissertation are as follows:

- 1) Identify and understand the range of structural barriers individuals with mental health challenges experience in higher education (Study 1).
- 2) Collaboratively explore a high priority structural barrier in greater depth, including potential solutions (Study 2).

### Participatory Practices within the Research Team

I will briefly describe participatory practices within the research team here, and I will also highlight links to participatory practices throughout the Methods section. The early stages of planning this dissertation were, to varying degrees, a product of my own decision-making. In preparation for the dissertation proposal, I informally consulted with a few students with lived experience of mental health challenges and professionals working with students with mental health challenges. However, there was no formal decision-making process for the involvement of such individuals. This was due to a number of constraints, including my efforts to acquire funding to support participatory involvement, which required me to propose a well-developed project in advance of having the resources to support participation (see McCartan et al., 2012). As well, given that this is a dissertation, approval of various parties, such as my supervisor and dissertation committee, also constrained both the timeline in which I could involve students with lived experience (i.e., I needed to have a design in mind and a proposed role for participatory

practices approved before I could engage in those practices), and the extent to which decision-making power could truly rest with students with lived experience of mental health challenges, as input from a variety of sources must be considered.

With this in mind, I will briefly describe our research team and the efforts I took to support participation and power sharing within the research team. Three current and former University of Victoria students with mental health challenges were hired as research assistants in April, 2021, and they have remained involved for the duration of this project. From April to August of 2021, these members were compensated at the hourly research assistant rate set by the University of Victoria, and they remained involved in the project as volunteers from September of 2021 until August 2022. Three additional current University of Victoria students with mental health challenges were recruited as volunteers to assist with workshop facilitation from December, 2021, to February, 2022. One of these facilitators remained part of our research team after the workshops, and two declined to continue involvement. Thus, from February 2021 onward our team was comprised of myself and four current and former University of Victoria undergraduate students with lived experience of mental health challenges. Within the research team, types of mental health challenges that team members identified with included mood disorders, anxiety disorders, trauma-related disorders, attention deficit/hyperactivity disorder, and autism spectrum disorder. The research team was all women, and within the group there was representation of various ages from early 20s to early 30s, sexual orientations, class backgrounds, ethnic backgrounds, racial minority status within Canada, and presence of cooccurring physical disability. The team was majority White and middle-class to upper middleclass, and evenly split in terms of sexual orientation and co-occurring physical disability.

This research team was developed to address various important components of participatory research, including facilitating trust and open sharing of participants and mitigating risks of harm to participants (Muhammad et al., 2015). In Study 1, the research team was involved in study design, recruitment, and interpretation of data. In Study 2, they were similarly involved in study design, recruitment, and interpretation of data, and were more directly involved in data collection as workshop facilitators.

Since April 2021, our research team has met weekly, with several breaks. We continued to meet during lulls in the research process to ensure that our work together was not solely focused on research tasks and what we planned to do, but also on our relationships with each other, reflection on our team, and reflection on our reactions to the findings so far (Bergold & Thomas, 2012; Lake & Wendland, 2018; Luttrell, 2000). We aimed to conduct our team in line with recommended practices for successful research partnerships, including being explicit about the extent to which different groups have decision-making power at different points (Lake & Wendland, 2018; Wong et al., 2010), normalizing that each team member makes unique contributions, and leaving space for us to learn from each other (Bergold & Thomas, 2012; Muhammad et al., 2015). We also aimed to be transparent on our research team, which included my own transparency about required outputs and timelines and that research is a slow process (Bergold & Thomas, 2012; Reason et al., 2011). Further, our regular meetings allowed us to discuss tensions and issues of power within the research team, including my own power within the research team and power dynamics between members of different backgrounds (e.g., students of colour vs. White students, students with lived experience of different mental health challenges; Muhammad et al., 2015). Thus, we have worked to foster an open and collaborative environment that is also pragmatic about what is realistic and achievable for this project. We

have practiced individual and team reflexivity within our discussions, including sharing reactions to findings, asking each other challenging questions about why certain decisions are being made, and reflecting on how our own positionality, both individually and as a research team, impacts the decisions we are making and our interpretations of data (Lake & Wendland, 2018; Muhammad et al., 2015; Reason et al., 2011).

# Chapter 2: Broad Survey of Impactful Barriers for Students with Mental Health Challenges

# **Study 1 Aims**

In Study 1, we aim to provide a more thorough investigation of structural stigma in higher education than has been completed previously. Structural stigma is defined as "societal level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and well-being of the stigmatized" (p. 2; Hatzenbuehler & Link, 2014). We aim to investigate experiences of structural stigma by providing prompts to participants that closer reflect their direct experience that results from such structural stigma (e.g., asking participants about the impact of a lack of available counselling services as opposed to the impact of the policies and funding structures responsible for this lack). Although there is much research to support that students with mental health challenges encounter structural barriers in university, the current study builds on this literature in several ways. Much of the previous research in this area is qualitative (e.g., Fossey et al., 2017; Giamos et al., 2017; Mullins & Preyde, 2013; Stein, 2013), while we make use of a quantitative survey. Qualitative research has been valuable for exploring lived experiences and identifying the range of structural barriers that students may face. However, quantitative methods offer the opportunity to expand what is known in several ways. Quantitative methods can allow for an investigation of the relative impact of different barriers, thus giving a sense of which barriers may be the highest priority for further investigation and action, which is a central aim of this work. Indeed, no study to our knowledge has attempted to gather quantitative data on a broad range of structural barriers, and thus such an investigation is needed to further understand how such barriers may cluster together to impact students.

Second, previous research has tended to focus on mental health status (i.e., the presence of mental illness or psychiatric disability) as the key demographic factor defining experience (e.g., Markoulakis & Kirsh, 2013; McEwan & Downie, 2013; Padron, 2006; Stein, 2013), and fails to investigate how barriers may differentially impact students of various backgrounds and identities. This is important, as the concept of intersectional stigma (Turan et al., 2019) suggests that individuals will experience stigma, including structural stigma, differently based on the convergence of multiple forms of marginalization. Further, previous research has not been able to determine the extent to which individuals may be impacted by barriers differently based on functional impact of their mental health challenges. This type of knowledge is important as it would help to elucidate the extent to which university systems may be better or less equipped to assist students with a range of severity of mental health challenges. Thus, our larger quantitative investigation allows us to explore to what degree aspects of an individual including their experience of mental health challenges may shape their experience of barriers.

Though quantitative methods give less opportunity for research participants to shape research questions and to direct their responses to what they may feel is most important, we have attempted to embed several aspects aligned with our participatory approach and our theoretical orientation within the survey. First, the survey was extensively revised by research assistants to use language that was non-stigmatizing and would capture the lived experience of participants. Second, participants had many opportunities to share responses in an open-text format, thus allowing them the opportunity to share or expand on important aspects that were not captured within the survey. These responses were not only limited to identifying further barriers, but also to understanding participant ideas for potential solutions and existing methods of support, thus honouring participant agency to resist or creatively manage the structural stigma they encounter.

Third, our team aimed to word questions in such a way that countered psychocentrism by clearly identifying barriers as structural, as opposed to as a result of individual failings, and thus we sought to promote epistemic justice by wording our items in such a way that acknowledged oppressive systems.

Thus, we aimed to answer four research questions in Study 1:

- 1) Which structural barriers are reported to be most impactful by current and former University of Victoria students with mental health challenges?
- 2) What are the various dimensions of structural barriers that students encounter?
- 3) Do barriers related to mental health challenges disproportionately impact individuals of marginalized social locations, and those with more impactful experiences of mental health challenges?
- 4) What strategies or supports do students utilize to navigate structural barriers?

#### Methods

#### **Participants**

Two hundred and seventy-five ( $M_{age}$  = 22.2 years, Range: 17 to 66 years) current and former University of Victoria students completed an online survey (see Table 1 for Demographic Information). Inclusion criteria were: 1) currently or formerly enrolled at the University of Victoria (not required to have graduated), and 2) identifies with having experienced challenges with their mental health during their time at the University of Victoria (see Table 2 for information about participant diagnoses and symptoms). We used multiple methods of recruitment, including, 1) recruitment via University of Victoria social media pages including student societies and academic departments, 2) the University of Victoria psychology undergraduate participant pool (n = 107), and 3) in-class announcements at the University of

Victoria made by the research team. Participants from the psychology undergraduate participant pool received bonus credit in their classes for participating, and all participants were given the option of entering their email into a draw for one of fifteen \$100 prizes to their choice of the UVic Bookstore, Amazon, or for donation to a community organization.

 Table 1

 Demographic Characteristics of Survey Participants

Characteristic	n	%
Gender		
Men	32	11.6
Transgender, nonbinary, or questioning	31	11.3
Women	210	76.4
No response	2	.7
Sexual Orientation*		
Asexual spectrum	19	6.9
Gay or lesbian	8	2.9
Heterosexual/straight	139	50.5
Bisexual, pansexual, and/or plurisexual	74	26.9
Queer	18	6.5
Questioning	8	2.9
No label	1	.4
No Response/gender identity response	16	5.8
Ethnic Background*		
Asian origins not otherwise specified	31	11.3
Caribbean origins	1	.4
East and Southeast Asian origins	35	12.7
European origins	61	22.2
Latin, Central and South American origins	4	1.5
Mixed origins not otherwise specified	1	.4
Oceania origins	1	.4
North American Indigenous origins	10	3.6
Other North American origins	25	9.1
Religious ethnic group (e.g., Christian, Muslim, Jewish)	23	8.4
South Asian Origins	9	3.3
West Central Asian and Middle Eastern origins	7	2.5

White, not otherwise specified	128	46.5
No response	20	7.3
Highest Education Level Achieved		
Grade 12	64	23.3
One year post-secondary	42	15.3
Two years post-secondary	43	15.6
Three years post-secondary	63	22.9
Four years post-secondary	31	11.3
Five years or more post-secondary	17	6.2
One year masters/doctoral work	6	2.2
Two years masters/doctoral work	4	1.5
Three years masters/doctoral work	1	.4
Five years masters/doctoral work	2	.7
No response	2	.7
Faculty		
Business	4	1.5
Education	9	3.3
Engineering	19	6.9
Fine Arts	15	5.5
Human & Social Development	10	3.6
Humanities	22	8.0
Law	4	1.5
Science	63	22.9
Social Sciences	129	46.9
Current Degree Status		
Currently completing degree	249	90.5
Former student with completed degree	18	6.5
Former student without completed degree	7	2.5
Racial Minority		
Yes	58	21.1
No	215	78.2
No response	2	.7
Financial Status		
Comfortable, with extra	67	24.4
Comfortable, but no extra	116	42.2
Have to cut back	75	27.3
Cannot make ends meet	17	6.2
	1,	J. <b>2</b>
First Generation Postsecondary Student		

Yes	60	21.8
No	215	78.2
Citizen of Canada		
Yes	250	90.9
No	24	8.7
No response	1	.4
Comorbid physical health concerns		
Yes	59	21.5
No	219	79.6

*Note.* \*Individuals were able to write as many sexual orientations and ethnic backgrounds as were applicable to them, and thus the total sexual orientations and ethnic backgrounds sums to greater than the total number of participants, and the percentages do not add up to 100%.

**Table 2** *Mental Health Diagnoses and Symptoms of Survey Participants* 

Characteristic	n	%
Mental Health or Neurodevelopmental Diagnosis*		
Anxiety disorder	155	56.4
Attention deficit/hyperactivity disorder	45	16.4
Autism spectrum disorder	7	2.5
Bipolar disorder	9	3.3
Borderline personality disorder	12	4.4
Depressive disorder	117	42.5
Eating disorder	15	5.5
Insomnia	1	.4
Learning disability	4	1.5
Obsessive-compulsive disorder	21	7.6
Post-traumatic stress disorder	25	9.1
Schizophrenia	2	.7
Sensory processing disorder	1	.4
Substance use disorder	3	1.1
No diagnosis	84	30.5
Symptoms*		
Impulsivity, excessive energy or joy, aggression, anger,		
easily frustrated, thrill-seeking behavior, unhealthy substance use	123	44.7

Self-injury (e.g., cutting, burning, skin-picking, hair-pulling)	97	35.3
Excessive sadness, low motivation, loss of pleasure, low self-worth, self-blame, suicidal ideation, worry (e.g., specific fears or worries, social situations, overarching worry), racing thoughts	246	89.5
High levels of stress or challenges related to experience of trauma/life stress (e.g., flashbacks, hypersensitive to surroundings, nightmares, detachment of reality, "blacking out")	166	60.4
Challenges with body image, extreme weight loss strategies, binge eating, fear of gaining weight	150	54.5
Challenges with social communication, changes in routine, physical touch, attention, concentration or learning, repetitive behaviors/movements (e.g., shaking, body rocking, head banging)	170	61.8
False beliefs of what one is seeing or hearing, disconnection from reality	47	17.1
Uncomfortable physical sensations (e.g., headaches, nausea/vomiting, fatigue, sleep disturbances, fidgety, racing heart, chest pain, dizzy, muscle tension)	188	68.4

*Note.* \*Individuals were able to write as many diagnoses and select as many symptoms as were applicable to them, and thus the total diagnoses and symptoms sum to greater than the total number of participants, and the percentages do not add up to 100%.

#### **Procedures**

Participants completed an online survey (created with SurveyMonkey) in a time and location of their choice. First, participants were presented with a consent form detailing the nature of the survey and the types of questions they could expect to answer. They then completed a self-report questionnaire that asked them about the impact of structural barriers they have faced in higher education. Participants were given the option to provide their contact information at the end of the survey, and were asked in what ways they are interested in contact: 1) for entry into a draw for a \$100 gift card, 2) to be contacted for participation in a workshop focused exploring structural barriers facing students with mental health challenges at the University of Victoria, and 3) to be e-mailed a newsletter on research findings and progress.

#### Measures

**Demographics.** Respondents completed a brief demographic questionnaire (see Appendix A). Participants provided open-text responses about age, gender, sexuality, ethnicity, major in university, physical health diagnoses, and mental illness diagnoses and self-diagnoses. They responded to questions with a set number of options about their occupational status, living situation, years of education, faculty, racial minority status, Indigeneity, degree status, citizenship, and whether they were a first-generation higher education student. Upon discussion within the research team, it was felt that concrete estimates of financial status and income would be unlikely to be accurate with this population, so we developed one item to measure financial strain where participants were asked to select whether their current financial situation was "comfortable, with extra," "comfortable, but no extra," "have to cut back," or "cannot make ends meet." We also developed a question focused on mental health symptoms which allowed individuals to select as many sets of symptoms as they may have, intended to assess the following sets of symptoms: 1) externalizing symptoms (e.g., aggression, impulsivity), 2) selfinjury, 3) internalizing symptoms (e.g., sadness, low self-worth, anxiety), 4) trauma symptoms, 5) eating-related symptoms, 6) neurodevelopmental disorder symptoms, 7) psychosis symptoms, and 8) physical symptoms associated with mental health (e.g., nausea/vomiting, fatigue, racing heart, muscle tension).

Structural Barriers to Higher Education. I chose to develop this scale for this research project as there are no existing scales that measure structural barriers to higher education for students with mental illness. I chose to design specific prompts about structural barriers as opposed to solely open-ended questions due to noted experiences of hermeneutical injustice (Leblanc & Kinsella, 2016), where students may not understand an experience as a structural

barrier due to the lack of interpretive resources available to make sense of experiences of discrimination in terms of structural, as opposed to individualistic, ways. My intention by providing prompts also was to address the saturation of data (Johannsen & Nicholas Angl, 2020) that occurs with continued consultation within communities by utilizing previously established information to move the conversation towards steps of assessing impact and prioritizing, as opposed to describing what has been described previously. The open-text questions in each section were intended to provide participants the opportunity to share more information and examples of structural barriers that were not captured within the current scale. I developed the initial version of this scale based on the literature of barriers to higher education for students with mental illness and in consultation with my supervisor, and it was refined through consultation with research team members with lived experience in order to ensure clarity and content coverage.

Our research team created a questionnaire about structural barriers to higher education for the purposes of this study (see Appendix B). This 54-item self-report questionnaire contained five sections that address different barriers within higher education (e.g., accommodations, services, information) that have been previously established in the literature. Each section contained specific questions about barriers a student may encounter, and open-ended questions. For example, under accommodations, participants were asked if they had encountered "Time delays in accessing the necessary services to acquire diagnosis or documentation for the Center for Accessible Learning." For each prompt, participants were asked to report whether they had encountered the barrier, and how much it negatively impacted them on a scale of 0 ("Not applicable/I have not encountered this barrier") to 4 ("I was very negatively impacted by this barrier"). At the end of each section, there were open-ended questions asking participants if they

have experienced any other structural barriers not listed, and what solutions or supports would be helpful in reducing barriers. At the end of the questionnaire, participants were asked several open-ended questions: "What strategies or supports have you found helpful in navigating post-secondary education?", "What would be the main structural change(s) that could be made in order to make post-secondary education more accessible?", "To what extent do you think these experiences are related to other aspects of your identity besides mental health challenges (e.g., race, culture, sexual or gender identity, physical disability)?", "What would you consider to be the top 5 most important barriers to address in higher education? These could be any of the barriers listed above, or any that are not listed."

Mental Health Functioning. Respondents completed several sections of the Short Form 36 Health Survey Questionnaire (SF-36; Ware & Sherbourn, 1992; Appendix C) to determine the impact of their mental health symptoms. The SF-36 measures impact of both physical and mental health symptoms, and we adapted the measure and selected items focused on mental health. Specifically, individuals were instructed to focus on how their mental health has impacted their life, and to focus on when their mental health was at its worst or lowest point during their time at the University of Victoria. The subscales *role limitations due to emotional problems* (3 items), *energy/fatigue* (4 items), and *emotional well-being* (5 items) were combined to create a mental health functioning score. Each item varies in the number of response options based on the question stem. Items are re-coded on a scale of 0 to 100, and scores are then averaged to result in a number between 0 and 100, with higher values indicating higher mental health functioning.

The alpha reliability coefficient for the combination of these items in the current sample was .81.

# Data Analysis

Frequencies of Barriers From Quantitative Ratings. To determine which barriers were reported most impactful by participants, I calculated average item scores. Scale items were placed in order from most highly impactful to least impactful as impactful, resulting in a "Top 10" most impactful barrier list.

Data Reduction of Structural Barriers to Higher Education Questionnaire. I conducted a principal components analysis to reduce the number of variables and determine key components of structural barriers measured by our questionnaire. I undertook this reduction for two purposes: 1) creating fewer components for follow-up analyses, reducing the number of comparisons and increasing variance among variables and 2) as this is a newly created questionnaire, to determine which components emerge. I chose principal components analysis over other methods of data reduction (e.g., factor analysis) because principal components analysis allows for indicators to *create* components, rather than, as in factor analysis, assuming that underlying latent factors are determining how individuals respond to the questionnaire (Bastos, 2021; Cornell Statistics Consulting Unit, 2020; Tabachnik & Fidell, 2001). Put another way, it is not the case that, for example, having a lack of knowledge of services in a variety of domains such as mental health, academic, and financial is caused by some underlying latent factor, but rather that the lack of knowledge in these domains combines together to result in an overarching lack of knowledge.

Principal components analysis is a method used primarily for data reduction, that is, to identify a set of fewer variables that can explain the variance present within a larger set of variables (Bryant & Yarnold, 1995). The principal components analysis was conducted using SPSS Statistics 28. Kaiser's stopping rule, which limits component extraction to eigenvectors

with eigenvalues of at least one, was used (Bryant & Yarnold, 1995). The principal components analysis was conducted using an oblique (promax) rotation, given that, theoretically, one would expect the components to be correlated (i.e., that experiencing barriers in one domain will correlate with experiencing barriers in another; Bryant & Yarnold, 1995). I ran two separate PCAs: one which utilized 33 items from the structural barriers questionnaires focused on knowledge, mental health care, and the culture of higher education, and one which utilized 16 items from the Centre for Accessible Learning (CAL) subscale. These PCAs were run separately because the full sample did not complete the CAL subscale, as participants had the option to skip this section if they did not have any prior experience with CAL. Total scores were created for each component by summing participant responses on the variables which comprised each component.

**Data Cleaning.** Missing data were minimal and were missing in a random pattern (i.e., there were no specific questions that large numbers of participants failed to answer). For participants missing small numbers of items (i.e., less than 15%) on the SF36 or components created from the Structural Barriers to Higher Education questionnaire, I used mean substitution to calculate their total score on the subscale.

Next, I analyzed full scale scores and continuous demographic data for skewness via visual inspection of frequency distributions. Age and education level both demonstrated high levels of skewness. As a result, I dichotomized age into groups below 25 and 26+, aligned with the typical age cut-off for emerging adulthood (Arnett, 2000). Education level was also skewed such that very few graduate students participated in the survey. Due to various confounds associated with graduate school (e.g., different learning environments and evaluation, not knowing whether graduate students started at UVic as undergraduates or graduate students),

graduate students were excluded from further analyses (*n*=13). The education level variable was no longer skewed after graduate students were dropped. Two components, "Misfit of CAL services" (3 items) and "Inappropriate Mental Health Services," (2 items) were highly skewed. As such, respondents were categorized as having not experienced the barrier (0), reporting low impact from the barrier (1), and reporting moderate to high impact from the barrier (2). Low impact ranged from a total score 1 to 2 for "Inappropriate Mental Health Services" and a total score of 1 to 3 for "Misfit of CAL services." For each scale, this range represents the possibility that participants experienced the barrier and reported a combination of no impact to a somewhat negative impact on one item. Above this range represents that participants would have had to rate at least one barrier as "somewhat impactful."

Impact of Structural Barriers to Higher Education by Demographics and Mental Health Challenges Severity. To provide a preliminary analysis of group differences in impact of structural barriers presumed to occur due to differences in experience of these barriers, I ran a series of hierarchical regression analyses. I completed these analyses for each component that emerged from the two PCAs, and for the individual item "Expectation of being your own advocate in health or mental health services," as this item did not load onto any components. For each component, I ran bivariate correlations between the component, mental health functioning as measured by the SF36, and demographic variables including age, gender minority status, sexual minority status, racial minority status, first-generation post-secondary student status, physical disability status, financial status, and education level. I included only those variables that were significantly correlated with the outcome variable in the hierarchical regression. For each component, mental health functioning was entered in a first step, and then, to determine if adding demographic variables significantly improved model fit, correlated demographic

variables were entered in a second step. I conducted this analysis to remove common variance among variables and thus determine which variables uniquely predict the experience of barriers. Identifying unique predictors in this way helps to disentangle which student groups may be uniquely impacted by barriers above and beyond effects due to mental health functioning alone. These analyses support a deeper understanding of how barriers are experienced by diverse groups of students and may help to identify methods to ameliorate barriers for those groups.

**Power Analysis.** I ran a power analysis post-hoc using G\*Power (Faul et al., 2009) to establish the statistical power to find significant effects in  $\Delta R^2$  within a linear regression analysis using data from my final, post-exclusions sample size. The analysis was run for small ( $f^2 = .02$ ), medium, ( $f^2 = .15$ ), and large ( $f^2 = .35$ ) effect sizes using the sample sizes for both the complete sample of participants with undergraduate education level (n=262) and the subset of participants who completed the CAL questionnaire (n=102). The number of predictors entered within the power analysis was six, which represents the greatest number of predictors within a given regression analysis. For both samples, power was adequate to detect medium and large effects (>.90), and for both samples power was insufficient to reliably detect small effects (power = .52 for full sample; power = .22 for CAL-specific sample).

New Barriers, Supports, and Solutions Identified from Qualitative Responses. I analyzed qualitative data to establish additional barriers, as well as participant suggestions of supports and solutions, using qualitative content analysis. Content analysis is a qualitative data analysis method that involves a relatively low level interpretation in order to classify qualitative data into distinct categories (Vaismoradi et al., 2013). Though it is suitable for presenting common categories and results within data, caution should be used for equating frequency with significance; it could also be that participants are more comfortable discussing certain issues as

opposed to others (Vaismoradi et al., 2013). As my aim of content analysis within this study is to discover new barriers and content, I used inductive content analysis, meaning I did not impose any preconceived categories or theories on the data (Hsieh & Shannon, 2005; Vaismoradi et al., 2013). This form of analysis includes three phases: 1) preparation, where researchers repeatedly read the data to become immersed and select the unit of analysis, 2) organising, which involves first open coding of the data, and then refinement into categories and higher order headings, and 3) reporting, which involves presenting results through models, conceptual maps, or categories (Hsieh & Shannon, 2005; Vaismoradi et al., 2013). In this study, partial data was coded twice: I coded all of the data myself, and research assistants coded half of different domains of data (i.e., one research assistant coded half of solutions data, another research assistant coded half of additional barriers data). We then met to discuss results and resolve discrepancies that occurred. Formal metrics such as interrater reliability have been cautioned against in content analysis. This is because, although they may suggest objectivity, interrater reliability can also be achieved by one researcher training others in their particular subjective interpretation of the data (Vaismoradi et al., 2013). Thus, separate coding and discussing inevitable discrepancies allowed for the research team to maintain their subjectivities and discuss meaningful differences in interpretation.

In practice, the preparation and organising of the qualitative coding proceeded differently based on the research question being addressed. For portions of the analysis that focused on identifying new barriers, particular attention was paid to those comments that indicated a barrier differed substantively in content from what was captured on our initial questionnaire. Such barriers were identified and narrowly coded to ensure clarity of the new barrier. Following the establishment of narrow codes signifying new items for the questionnaire, the new items were

categorized into themes based on having similar substantive content in order to identify overarching areas that were missed in the initial questionnaire. Frequency was not considered during this part of the analysis, as the purpose was expressly to find those barriers which are *less* common and thus more likely to be missed.

Coding proceeded in a similar fashion for data related to proposed solutions, with the exception that themes were not developed in relation to solutions. Thus, data related to proposed solutions was narrowly coded to identify specific ideas for improvements that were shared among participants. Rather than further interpret this data by generating broader overarching themes, I ceased analyzing the data at this narrow level, since the purpose of this analysis is to provide specific suggestions to various services, and further interpretation may only obscure the clarity of proposed solutions.

For coding data related to existing supports, data were first coded more narrowly to determine specific types of support that were helpful, and then combined into broader categories representing the range of supports participants reported. These broader categories are presented, with narrative presentation of more specific forms of supports identified within each category.

## **Quantitative Results**

#### Top 10 Most Impactful Barriers

To determine which individual barriers were rated as most impactful by students, I computed averages for all of the items on the structural barriers questionnaire (see Table 3 for top 10 most highly rated barriers). Barriers within the top 10 represented a range of concerns, including self-advocacy, learning-related barriers, disclosure-related barriers, and administrative barriers. Such a list is intended to be locally specific, and highlights where the greatest impact is experienced by UVic students with mental health challenges.

Table 3

Top 10 Most Impactful Barriers

	Mean	Standard Deviation
Barriers related to "typical" university evaluation (e.g., timed tests, strict academic schedules/due dates).	2.64	1.26
Expectation of being your own advocate in health or mental health services.	2.48	1.29
Feeling burdened or overwhelmed by paperwork involved in returning to academics after leaving and returning to school.	2.41	1.39
Navigating health and mental health services without guidance.	2.38	1.24
Experiencing time-delays in access to services (e.g., being on a waitlist).	2.32	1.54
Stress or negative emotion related to the process of disclosing your diagnosis/experience to others for the purpose of accessing academic support and/or accommodations.	2.30	1.28
Stress or negative emotion related to the process of disclosing your diagnosis/experience to others.	2.21	1.42
Fears that acquiring accommodations will lead to unwanted disclosure of your experience/diagnosis to professors, peers, or future employers.	2.20	1.27
Barriers related to learning in the "typical" university classroom (e.g., busy lecture halls, set lecture times).	2.19	1.28
Lack of counselling services available that meet your needs.	2.17	1.43

Learning environment barriers related to evaluation and classroom environment were both ranked in the top 10 most impactful barriers, aligning with literature that post-secondary institutions are set up for "one type of learner" (Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013). Two items pertaining to self-advocacy related barriers were also in the top 10 most impactful barriers. Some previous literature has identified that self-advocacy is a problematic expectation for university students with mental health challenges, as the often developmentally later diagnosis of mental health challenges (versus learning or physical health challenges) means that students may be ill-prepared with knowledge of themselves and their rights to successfully advocate (McEwan & Downie, 2013). Additionally, some symptoms of mental health challenges can make self-advocacy very difficult or impossible (Bruce & Aylward, 2021), and at times when students do self-advocate, university systems do not have adequate supports to offer them (Bruce & Aylward, 2021).

Disclosure-related barriers accounted for three of the top 10 identified barriers. These are important barriers to attend to, as often receiving services and supports requires student disclosure. Disclosure-related barriers have received much attention in the literature, with clear identification that students are uncomfortable doing so both for fear of negative interactions with others, and for fear of negatively impacting future academic and career prospects (Hartrey et al., 2017; Kain et al., 2019; Kruse & Oswal, 2018; Lindsay et al., 2018; Magnus & Tøssebro, 2014; Markoulakis & Kirsh, 2013; Padron, 2006; Stein, 2013; Venville et al., 2014b). Importantly, there is evidence of the real potential for such disclosures to impact opportunities and others' views of students, as both negative views and ratings of lower desirability for graduate school have been noted in response to disclosures of mental illness (Appleby & Appleby, 2006; Knis-Matthews et al., 2007; Magnus & Tøssebro, 2014; Venville et al., 2014b; Zöld et al., 2020).

Mental health services related barriers were present in two of the top 10 most imapctful barriers, including time delays in accessing services and overall inadequacy of counselling services. Though time delays in services have been noted elsewhere (Chang et al., 2020; Hartrey et al., 2017; Markoulakis & Kirsh, 2013), the strength of the impact of this barrier may indicate service limitations unique to the University of Victoria context.

One barrier related to the process of taking a leave, the burdensomeness of associated paperwork, was identified among the top 10 barriers. A much smaller portion of our full sample responded to leave-related questions (n=68), meaning that, while much of our sample wasn't affected by this barrier as they had not gone through the process of leaving and returning to school, those who did reported a great degree of impact. Wigginton's (2017) dissertation focused on the topic of mental health related leaves and clearly identified that, although leaves can be seen as important and necessary steps for students with mental health challenges, they are often laden with barriers. Research specific to mental health related leaves reminds minimal. The relative invisibility of this set of barriers which likely disproportionately impacts students with mental health challenges necessitates more research.

## Principal Components Analysis

Mental Health Services Barriers, Knowledge Barriers, and University Culture-Related Barriers. To reduce the number of variables and determine key components of structural barriers measured within our questionnaire, a principal components analysis was conducted on 33 items of the structural barriers questionnaire. Specifically, the items related to knowledge barriers, mental health and health services barriers, and university culture barriers were included in the PCA. The items related to the Centre for Accessible Learning and to students who have taken a leave were not included, as a smaller subset of participants had

completed those sections due to their irrelevancy for some participants (n = 102 for CAL questions, n = 68 for leave questions).

Kaiser Meyer Olkin's test of sampling adequacy was .922, indicating excellent sampling adequacy (Hutcheson, 2020). The PCA was run using an oblique (promax) rotation given the expected correlated nature of the components. Using Kaiser's stopping rule, the PCA resulted in seven components with eigenvalues above 1. For individual items, a loading size of .40 was used to determine loading onto a component, and loadings above .30 were considered for cross-loadings. One item ("Expectation of being your own advocate in health or mental health services") failed to load above .30 on any factors. Cross-loadings, wherein an item loaded above .30 on more than one component, occurred for five items. Because the purpose of this PCA was to reduce data for follow-up analyses (as opposed to for scale development), cross-loaded items were retained and placed within a component based on the theoretical coherence of the item within the component. This resulted in components that were theoretically coherent and captured as much of the original scale within the components as possible, and minimized loss of data in the process of data reduction.

The seven components that resulted from the PCA represent seven unique domains of barriers (see Table 4): 1) barriers in mental health care, 2) stigma and negative interpersonal interactions, 3) navigation of services barriers, 4) practical support knowledge barriers, 5) financial barriers, 6) learning barriers, and 7) inappropriate mental health services. Correlations between components are in Table 5.

**Table 4** *Mental Health Services, Knowledge, and University Culture-Related Barriers Principal Components Analysis Results* 

Item	1	2	3	4	5	6	7
Barr	iers in Mental	Health	Care				

Experiencing time-delays in access to services (e.g., being on a waitlist).	.879
Challenges coordinating your care between services or appointments.	.878
Lack of follow-up or ongoing support from mental health services.	.866
Other barriers to accessing mental health services (e.g., limited hours of operation).	.860
Lack of counselling services available that meet your needs.	.801
Difficulty of the process for accessing and maintaining continued access to care (e.g., paperwork, following up with providers).	.704
Lack of involvement in the continuation of services outside of the university (e.g., not getting referrals to other mental health services).	.693
Lack of psychiatrist services available that meet your needs.	.588

Stigma and Negative	Interpersonal Interactions	
Having others assume unrelated issues or concerns are associated with one's mental health challenges.	.847	
Others' beliefs that you are "faking" your experience in order to receive special privileges.	.807	
Hearing negative beliefs or stereotypes about individuals with mental health challenges (e.g., that individuals with mental illness are unfit for certain professions, that they exaggerate their symptoms to get special privileges) from other students.	.778	
Hearing negative beliefs or stereotypes about individuals with mental illness (e.g., that individuals with mental illness are unfit for certain professions, that they exaggerate their symptoms to get special privileges) from university faculty or staff.	.752303	

Lack of privacy or increased surveillance	.727	
due to your experience/diagnosis.		
Hearing negative beliefs or stereotypes	.603	.312
about individuals with mental illness from		
mental health service providers.		
Stress or negative emotion related to the	.481	
process of disclosing your		
diagnosis/experience to others.		
Lack of information shared on	.458	
medications prescribed during an		
encounter with a health or mental health		
professional.		

Navigation (	of Services Ba	arriers			
Lack of knowledge about how to access non-clinical mental health support (e.g., peer support, holistic approaches).		.882			
Lack of knowledge about how to access clinical mental health support (e.g., counsellors, doctors, psychiatrists).		.833			
Lack of knowledge of the role of different professionals in mental health services (e.g., psychologist and psychiatrist, counsellor and registered counsellor, etc).		.669			
Navigating health and mental health services without guidance.		.527			
Lack of knowledge about how to access academic support.		.509	.429	306	
Lack of alternative or peer-run mental health services (e.g., peer support, holistic approaches).		.494			
Lack of a spokesperson or advocate on your behalf for accessing mental health services.	.358	.452			

# Practical Support Knowledge Barriers

.850

Lack of awareness that your experience/diagnosis qualified you for academic accommodations through the CAL.

Lack of knowledge about available types of support from the CAL (e.g., borrowed laptops, noise-cancelling headphones).	.747			
Lack of knowledge of funding opportunities for students with diagnosed mental illnesses.	.613	.322		
Financial Barriers				
Financial barriers to accessing mental health services.		.845		
Financial barriers in accessing prescribed medication.		.832		
Learning Barriers				
Barriers related to learning in the "typical"			.789	
university classroom (e.g., busy lecture halls, set lecture times).				
Barriers related to "typical" university evaluation (e.g., timed tests, strict academic schedules/due dates).			.785	
Inappropriate Mental Health S	Services			
Lack of mental health support that is				.819
appropriate to your cultural background.				
Feeling pressured into receiving services you would not otherwise access.				.775
No Loading				
Expectation of being your own advocate				
in health or mental health services.				

Table 5

Component Correlation Matrix

	1	2	3	4	5	6	7
1		.59	.62	.43	.49	.20	.28
2			.54	.44	.49	.31	.39
3				.47	.40	.23	.26
4					41	28	19

5 .09 .28 6 .03

Centre for Accessible Learning Barriers. Because the full sample did not complete the questions related to the Centre for Accessible Learning portion of the questionnaire, I ran a separate PCA for these items. The PCA was completed in the manner described above. Kaiser

Meyer Olkin's test of sampling adequacy was .832, indicating good sampling adequacy (Hutcheson, 2020). Using Kaiser's stopping rule, the PCA resulted in four components with eigenvalues above one. Cross-loadings, defined as an item loading above .30 on more than one component, occurred for five items, and were dealt with in the same manner as described in the previous PCA. The four components that resulted from the PCA represent four unique domains of barriers (see Table 6): 1) Helpfulness of CAL Services, 2) Misfit of CAL services, 3) Disclosure-Related Barriers, and 4) Administrative Barriers. Correlations between components are in Table 7.

 Table 6

 Center for Accessible Learning Principle Components Analysis Results

Item	1	2	3	4
Helpfulness of C	AL Services	S		
Inconsistent implementation of accommodations in courses (e.g., varying accommodation resources applied from one class to another).	.791			
Lack of follow-up from CAL or instructors regarding whether your accommodations are appropriate/helpful.	.735			
Navigating the CAL services without adequate or appropriate guidance.	.468			
Negative comments or skepticism from others (e.g., CAL staff, professors, students) about your accommodations.	.465	.428		
Being able to access CAL but the accommodations provided are not appropriate/helpful.	.453	.302		
Misfit of CAI	Services			
Lack of culturally diverse representation in CAL staff.		.820		
Being assigned a CAL advisor that is not adequate for meeting your support needs.	.320	.678		
Discontinuation of support from CAL without consent.		.653		

Disclosure-Relate	ed Barriers			
Fears that acquiring accommodations will negatively affect your marks in class or your treatment/experience within the class.			.861	
Stress or negative emotion related to the process of disclosing your diagnosis/experience to others for the purpose of accessing academic support and/or accommodations.			.737	
Fear or not wanting a documented mental illness that could have other consequences (e.g., relationships with others, student loans, future career prospects, etc.)		.353	.642	
Fears that acquiring accommodations will lead to unwanted disclosure of your experience/diagnosis to professors, peers, or future employers.	.665		.418	
Administrative	Barriers			
Time delays accessing the necessary services to acquire diagnosis or documentation for the Center for Accessible Learning (CAL).				.738
Inability to receive adequate diagnosis to access accommodations through the CAL.				.709
<b>Financial barriers</b> to accessing the necessary services to acquire diagnosis or documentation for the CAL.				.649
Feeling burdened or overwhelmed by paperwork involved in accessing accommodations.	.432			.635

Table 7

<u>Center for Accessible Learning Component Correlation Matrix</u>

	J			
	1	2	3	4
1		.37	.38	.40
2			.20	.26
3				.31

Unsurprisingly, given that the questionnaire was largely developed by review of previous literature, the dimensions identified for both the general and CAL-specific barriers represent a broad range of barriers identified in the literature, especially the dimensions of barriers in mental health care (Chang et al., 2020; Hartrey et al., 2017; Markoulakis & Kirsh, 2013; Marsh & Wilcoxon, 2015; Venville et al., 2016), stigma and negative interpersonal interactions (O'Shea & Kaplan, 2018; Padron, 2006; Stein, 2014) practical support knowledge barriers (Chambers et al., 2013; Hartrey et al., 2017; McEwan & Downie, 2013), financial barriers (Hartley, 2010; Marsh & Wilcoxon, 2015; Megivern et al., 2003), learning barriers (Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013), helpfulness of CAL services (Fossey et al., 2017; Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013), CAL disclosure-related barriers (Kruse & Oswal, 2018; Padron, 2006; Stein, 2013), and CAL administrative barriers (Chambers et al., 2013; Giamos et al., 2017).

Several of the identified dimensions were less aligned with previous literature. Although lack of knowledge of various services and supports has clearly been identified in the literature (Fossey et al., 2017; Giamos et al., 2017; Hartrey et al., 2017; Lindsay et al., 2018; Megivern et al., 2003; O'Shea & Kaplan, 2018), such lack of knowledge clustered with overall service navigation barriers, including those related to lack of advocacy and lack of available peer-support services. We named this dimension "navigation of service barriers," as it comprises more than barriers associated with lack of knowledge, but a variety of tools that students could use to navigate, but cannot access. Such overarching barriers of lack of ability to navigate across the various services on offer are much less commonly discussed in the literature.

Further, two similar sets of barriers, inappropriate mental health services and misfit of CAL services, both represented services that were inappropriate for various reasons, including

cultural inappropriateness, coerciveness, and non-transparency. Such barriers are also less commonly discussed in the literature specific to university, though cultural irrelevancy and coercion within mental health care has been identified often elsewhere (e.g., McKenzie & Bhui, 2007; Nwokoroku et al., 2022; Rabiee & Smith, 2014). Thus, literature to date may be inadequately attending to barriers that impact specific marginalized groups.

# Structural Barriers Associations with Mental Health and Demographic Variables

**Preliminary Analyses.** The means, standard deviations, range, and  $\alpha$  coefficients for the subscales resulting from the PCA are in Table 8. The items from the "Leave" subscale of the original Structural Barriers Questionnaire were excluded from analysis due to the small number of participants who completed those items (n = 68). With the exception of Misfit of CAL services, responses represented the full range of impact captured by the scale. Many of the mean scale scores fell around the midpoint of the scale, with the exception of the stigma/interpersonal, inappropriate mental health services, and misfit of CAL services subscales. Such subscales may impact a smaller subset of the current sample, and thus may have lower means due to their inequitable distribution among the sample.

**Table 8**Subscale Descriptive Statistics and Reliability

		Standard			
	Mean	deviation	Minimum	Maximum*	α
Mental Health Care Barriers	15.18	9.35	0	32	.92
Stigma/ Interpersonal	11.51	7.76	0	32	.87
Navigation of Services	12.71	6.47	0	28	.86
Practical Support Knowledge	5.52	3.35	0	12	.75

Financial Barriers	3.05	2.45	0	8	.70
Learning Barriers	4.83	2.27	0	8	.75
Inappropriate Mental Health					
Services	1.62	1.96	0	8	.63
Self-Advocacy Barriers	2.48	1.29	0	4	N/A
** 1 0 1 0					
Helpfulness of CAL Services	8.32	4.84	0	20	.80
Misfit of CAL Services	2.15	2.68	0	10	.74
D:1					
Disclosure- Related Barriers	8.66	4.05	0	16	.79
Administrative					
Barriers	7.16	3.67	0	16	.69

*Note.* \*Scales have different possible maximum values. Respondent range represents the full possible range of subscale values with the exception of Misfit of CAL Services, where the possible maximum score was 12.

To determine whether to use the faculty in which the student was enrolled in follow-up analyses, independent samples t-tests were completed to determine whether between-group differences existed on any of the structural barriers subscales. There was a small representation of students from many faculties (see Table 1), and thus Sciences (n = 63) and Social Sciences (n = 129) were compared for mean differences, as these two faculties would be the only sufficiently powered to use in follow-up analyses. There were no significant differences, and thus this variable was not utilized in further analyses.

Three categories of gender were represented within the present sample: 1) men, 2) transgender, nonbinary, or questioning, and 3) women. To determine how to proceed with these

gender categories within further analyses, one-way ANOVAs were run to determine differences in mean scores between genders on the structural barriers subscales. Tukey's post-hoc tests were used to determine between which groups significant differences existed. No significant differences were identified between men and women on any of the subscales. Throughout the analyses, transgender, nonbinary, or questioning means differed significantly from either men, women, or both men and women (see Table 9). This aligns with previous findings that gender minorities experience worse mental health than cis-gendered individuals (Lipson et al., 2019; Slemon et al., 2022), and that such experiences are largely rooted in stigma and systemic discrimination (Valdisseri et al., 2021). Thus, the differences we found may represent both greater need for support among gender minorities, and greater discriminatory barriers encountered in accessing support. For follow-up analyses, men and women were grouped together due to the lack of significant differences between them, and compared with transgender, nonbinary, or questioning respondents, termed "gender minority status" within the follow-up analyses.

**Table 9**Gender Differences of Impact of Barriers

Component	<i>F</i> -statistic	p	$\eta_2$	Gender comparisons	Mean difference (A-B) [95% CI]	p
Stigma	4.23*	0.016	.03	Women (A) x Men (B)	2.46 [96, 5.88]	.210
				Women (A) x Trans/Non-Binary (B)	-3.13 [-6.59, .34]	.087
				Men (A) x Trans/Non-Binary (B)	-5.58* [-10.12, -1.04]	.011
Mental Health Services Barriers	6.97**	.001	.05	Women (A) x Men (B)	2.86 [-1.25, 6.97]	.231
				Women (A) x Trans/Non-Binary (B)	-5.50** [-9.66, -1.33]	.006

Service Navigation	2.39	.094	.017	Men (A) x Trans/Non-Binary (B)	-8.36** [-13.81, -2.90]	.001
Barriers						
Knowledge of Practical Supports	5.19**	.006	.04	Women (A) x Men (B)	.91 [57, 2.38]	.315
T off				Women (A) x Trans/Non-Binary (B)	-1.69* [-3.18,19]	.023
				Men (A) x Trans/Non-Binary (B)	-2.60** [-4.56,64]	.006
Financial Barriers	7.69**	.0006	.05	Women (A) x Men (B)	.87 [22, 1.95]	.145
Burriers				Women (A) x Trans/Non-Binary (B)	-1.46** [-2.54,37]	.005
				Men (A) x Trans/Non-Binary (B)	-2.32** [-3.75,89]	.0005
Learning Barriers	4.11*	.018	.03	Women (A) x Men (B)	.99 [01, 2.00]	.054
				Women (A) x Trans/Non-Binary (B)	58 [-1.60, .43]	.367
				Men (A) x Trans/Non-Binary (B)	-1.58* [-2.91,24]	.016
Inappropriate Mental Health Services	.45	.638	.003	• ( )	- <u>-</u>	

*Note.* \* indicates p < .05; \*\* indicates p < .01.

Correlations between each subscale with mental health symptoms and demographic variables can be found in Table 10 for the subscales to which all participants responded, and Table 11 for the CAL-specific subscales. For correlations with subscales comprised of items completed by all participants, mental health functioning was negatively correlated with all the subscales, such that lower mental health functioning was related to greater impact of barriers. Correlations with demographic variables differed by subscale, with financial status and physical disability most commonly correlated with the subscale variables. For CAL-specific subscales, mental health functioning was correlated in the expected direction for both disclosure-related

barriers and administrative barriers, and was not significantly correlated to the other subscales. Overall, demographic predictors were less correlated with CAL-specific subscales as opposed to general subscales. The Helpfulness of CAL Services subscale was only significantly correlated with physical disability, and the Misfit of CAL Services subscale was only significantly correlated with racial minority status. Thus, no follow-up hierarchical regression was run for these subscales.

 Table 10

 Correlations among Structural Barriers Components, Mental Health, and Demographics

	Mental	Stigma/	Service	Practical	Financial	Learning	Inappropriate	Self-
	Health Care	Interpersonal	Navigation	Support	Barriers	Barriers	Mental Health	Advocacy
	Barriers (p)	<i>(p)</i>	<i>(p)</i>	Knowledge (p)	<i>(p)</i>	<i>(p)</i>	Services (p)	Culture (p)
1.Mental health functioning	<b>44**</b> (<.001)	<b>34**</b> (<.001)	<b>34**</b> (<.001)	<b>33**</b> (<.001)	<b>33**</b> (<.001)	<b>39**</b> (<.001)	<b>13*</b> (.034)	<b>39**</b> (<.001)
2.Age	.10 (.093)	.04 (.476)	.09	.07	.15* (.014)	.05	.06 (.348)	.10 (.100)
3.Gender minority status	<b>.20**</b> (<.001)	<b>.14*</b> (.019)	.09 (.131)	.17** (.004)	<b>.20**</b> (.001)	.10 (.098)	.02 (.725)	<b>.20**</b> (.001)
4.Sexual minority status	<b>.23**</b> (<.001)	.11 (.078)	<b>.17**</b> (.007)	<b>.27**</b> (<.001)	<b>.16*</b> (.011)	<b>.16*</b> (.013)	05 (.456)	<b>.28**</b> (<.001)
5.Racial minority status	.02 (.765)	.08 (.183)	.01 (.932)	<b>06</b> (.317)	.10 (.106)	<.01 (.982)	.35** (<.001)	<b>02</b> (.747)
6.First generation post-secondary status	<b>05</b> (.400)	.05 (.428)	.06 (.336)	.01 (.827)	.11 (.067)	<b>01</b> (.871)	.13* (.029)	.01 (.913)
7.Physical disability status	<b>.18**</b> (.003)	.12* (.048)	<b>.15*</b> (.012)	<b>.16**</b> (.007)	.12* (.047)	<b>.16**</b> (.009)	<.01 (.985)	<b>.24**</b> (<.001)
8.Financial stress	.26** (<.001)	<b>.28**</b> (<.001)	<b>.23**</b> (<.001)	<b>.30**</b> (<.001)	<b>.46**</b> (<.001)	<b>.24**</b> (<.001)	.07 (.230)	<b>.27**</b> (<.001)
9.Education level	.19** (.002)	.01 (.888)	.10 (.115)	.09 (.166)	.12 (.065)	.06 (.318)	<b>06</b> (.360)	.05 (.410)

*Note.* \* indicates p < .05; \*\* indicates p < .01.

Table 11

Correlations among CAL Components, Mental Health, and Demographics

	Helpfulness of CAL Services ( <i>p</i> )	Misfit of CAL Services ( <i>p</i> )	Disclosure-Related Barriers ( <i>p</i> )	Administrative Barriers ( <i>p</i> )
1.Mental health functioning	17 (.081)	10 (.331)	<b>27**</b> (.007)	<b>26**</b> (.008)
2.Age	<.01 (.978)	.04 (.685)	30 (.767)	01 (.918)
3.Gender minority status	.15 (.125)	<b>06</b> (.563)	.07 (.458)	.14 (.158)
4.Sexual minority status	.19 (.058)	.07 (.478)	.19 (.067)	.18 (.077)
5.Racial minority status	.17 (.086)	<b>.32**</b> (.001)	.05 (.620)	.10 (.338)
6.First generation post-secondary status	.15 (.146)	.07	.08 (415)	.12 (.222)
7.Physical disability status	<b>.24*</b> (.014)	.04 (.670)	.06 (.573)	.20* (.043)
8.Financial stress	.14 (.162)	<.01 (.974)	<b>.24*</b> (.016)	<b>.25*</b> (.011)
9.Education level	.19 (.072)	.17 (.106)	.13 (.202)	.10 (.379)

*Note.* \* indicates p < .05; \*\* indicates p < .01.

Intercorrelations between mental health functioning and potential demographic predictors were also run (see Table 12). Mental health functioning was significantly correlated with being a gender minority, sexual minority, or racial minority, and reporting greater financial strain. While some demographic variables were moderately correlated (i.e., gender minority status and sexual minority status), none were highly correlated, and many were unrelated to each other. This relative statistical independence supports the use of such variables within follow-up hierarchical regression analyses, as we did not observe high degrees of multicollinearity that would negatively impact regression results including all variables.

 Table 12

 Correlations among Mental Health Functioning and Demographic Predictors

	1	2(p)	3( <i>p</i> )	4(p)	5( <i>p</i> )	6(p)	7(p)	8(p)	9(p)
1.Mental health		07	17**	22**	14*	.05	09	29**	08
functioning		(.280)	(.006)	(.0004)	(.025)	(.464)	(.125)	$(1.00 \times 10^{-6})$	(.164)
2.Age			.04	.05	10	.14*	.13*	.24**	.30**
2.0 1			(.517)	(.397)	(.108)	(.018)	(.035)	$(5.00 \times 10^{-5})$	$(1.29 \times 10^{-13})$
3.Gender				.40**	10	05	.27**	.15*	.06
minority status				$(3.13x10^{-11})$	(.117)	(.433)	$(9.0x10^{-6})$	(.013)	(.300)
4.Sexual					23**	.03	.22**	.11	03
minority status					(.0002)	(.634)	(.0004)	(.070)	(.689)
5.Racial						.09	16**	.08	05
minority status						(.130)	(.010)	(.165)	(.375)
6.First							08	.12*	03
generation post-							(.192)	(.045)	(.654)
secondary status									
7.Physical								.001	.19**
disability status								(.981)	(.002)
8.Financial									.07
stress									(.257)
9.Education									
level									

level *Note.* \* indicates p < .05; \*\* indicates p < .01.

Financial strain was the most highly correlated with mental health functioning among all demographic predictors. There is ample evidence of a close link between financial strain and mental health, with unmet social determinants of health and, in some cases, specifically financial stress as both contributing to adverse mental health outcomes among university students (Johnson et al., 2021). Students may be especially likely to experience to experience financial stress due to the time and financial demands associated with school, including the cost of school itself and cost of living (Chaplot et al., 2015; Joo, Durband, & Grable, 2008; Tinklin, Riddell, & Wilson, 2005). As was discussed previously, the finding that gender minorities experience worse mental health is consistent with past literature, with stigma and discrimination being a key mechanism of this disparity (Valdisseri et al., 2019). The same has been found for racial minority students: that such students have lower mental health than White students, and that this association is partially explained by discrimination (Cokley et al., 2011). Similarly, sexual minority students report more psychological distress and mental health-related academic impairment than heterosexual students, and thus have to manage academic expectations along with various mental health and social stressors associated with sexuality (Alessi et al., 2017; Dunbar et al., 2017).

Examining Mental Health Functioning and Demographic Relationships with

Structural Barriers. In order to determine the degree to which particular student groups may

disproportionately experience certain structural barriers, a series of hierarchical regression

analyses were run. Results will be discussed in relation to the previous literature and our team's

reflections, with a summary of the overarching roles of functional impact of mental health

challenges and financial stress at the end of this section given the pervasiveness of the role of
these two factors.

Mental Health Care Barriers. In order to investigate the extent to which correlated demographic variables uniquely predicted mental health care barriers when mental health functioning was controlled for, I ran a hierarchical regression analysis in which correlated demographic variables and mental health functioning were regressed onto mental health care barriers (see Table 13). Results of the first step of the regression, which included mental health functioning, replicated the correlational results I have already presented in Table 10. The second, and focal step in the regression model included the demographic variables that were correlated with the outcome variable: gender minority status, education level, sexual minority status, financial stress, and physical disability status. Including these variables in the model improved model fit,  $\Delta R^2 = .07$ , F(5, 232) = 4.56, p = .001. Education level uniquely predicted mental health care barriers, such that higher education level was associated with higher reported impact of barriers. Although there is, to my knowledge, no research on how the number of years in university is associated with experience of barriers among students with mental health challenges, there is evidence that students in their first year are less likely to access services than those later in their degree (Oswalt et al., 2019). Thus, it is plausible that upper year students experience more barriers related to mental health care because they have made more attempts to access such care.

Table 13

Regression results using Mental Health Care Barriers

Predictor	<i>b</i> [95% CI]	p	β	sr <sup>2</sup>	Fit
Step 1  Mental health functioning	-0.27 [-0.35, -0.20]	<.001	44	.19	$R^2 = .19$ $p < .001$
Step 2					
Mental health functioning	-0.22 [-0.29, -0.14]	<.001	35	.10	
Gender minority status	1.50 [-2.01, 5.05]	.410	.05	.002	
Education Level	0.80 [0.13, 1.47]	.020	.14	.02	
Sexual minority status	2.04 [-0.27, 4.35]	.084	.11	.01	
Financial stress	1.19 [-0.07, 2.5]	.064	.11	.01	
Physical disability status	2.47 [-0.16, 5.09]	.066	.11	.01	
and					$R^2 = .26$

Stigma and Negative Interpersonal Interactions. I next used a similar regression to predict stigma and negative interpersonal interactions (see Table 14). Here, the second focal step of the analysis significantly improved model fit,  $\Delta R^2 = .04$ , F(3, 265) = 4.37 p = .005. Financial stress additionally uniquely predicted impact, such that greater financial stress was associated with higher reported impact of stigma and negative interpersonal interactions.

**Table 14**Regression results using Stigma and Negative Interpersonal Interactions

Predictor	b [95%CI]	p	β	$sr^2$	Fit
Step 1  Mental health functioning	-0.19 [-0.25, -0.13]	<.001	34	.12	$R^2 = .12$ $p < .001$
Step 2					
Mental health functioning	-0.15 [-0.21, -0.09]	<.001	28	.07	
Gender minority status	1.09 [-1.75, 3.93]	.451	.05	.002	
Financial stress	1.65 [0.59, 2.70]	.002	.18	.29	
Physical disability status	1.55 [-0.63, 3.72]	.162	.08	.006	
disability status					$R^2 = .16$

One of our research assistants who identified as being under financial strain resonated with this finding. This research assistant shared their own experience of feeling ashamed and not wanting to disclose their financial status when service providers recommended options with a cost associated, fearing they would be viewed more negatively if this were known. This feeling has been noted among university students with lower socioeconomic backgrounds, specifically, that such individuals have less social capital, which has the potential to mitigate stigma associated with disability, and thus assumed they would be subjected to greater stigmatization due to the intersection of class and disability (Waterfield & Whelan, 2017). This offers a

potential mechanism by which barriers associated with stigma are exacerbated among those with both mental health challenges and experiencing financial strain.

Service Navigation Barriers. I once again used a similar regression to predict service navigation barriers (see Table 15), and once again the second step of the model significantly improved model fit,  $\Delta R^2 = .04$ , F(3, 251) = 3.73 p = .01. Both financial stress and physical disability status uniquely predicted service navigation barriers, such that more financial stress was related to more impactful barriers, and having a physical disability was associated with more impactful barriers. This aligns with findings among samples that combine physical disability and mental health challenges of service navigation difficulties of lack of knowledge of services, challenges locating services, and a lack of connection between services (Fleming et al., 2017).

**Table 15** *Regression results using Service Navigation Barriers* 

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Practical Support Knowledge Barriers. I used a parallel regression to predict practical support knowledge barriers (see Table 16). The second step improved model fit,  $\Delta R^2 = .10$ , F(4, 248) = 7.25 p < .001. Sexual minority status was a significant predictor such that being a sexual minority was related to greater impact of practical support knowledge barriers. Financial stress was also a significant predictor, such that more financial stress was related to greater impact of practical support knowledge barriers.

 Table 16

 Regression results using Knowledge and Practical Support Barriers

Predictor	<i>b</i> [95% CI]	p	β	$sr^2$	Fit
Step 1  Mental health functioning	-0.08 [-0.11, -0.05]	<.001	34	.12	$R^2 = .12$ $p < .001$
Step 2  Mental health functioning	-0.05 [-0.08, -0.03]	<.001	23	.04	
Gender minority status	-0.02 [-1.30, 1.26]	.979	002	<.001	
Sexual minority status	1.20 [0.36, 2.03]	.005	.18	.03	
Financial stress	0.89 [0.43, 1.35]	<.001	.23	.05	
Physical disability status	0.81 [-0.13, 1.75]	.091	.10	.009	
					$R^2 = .21$

There is evidence that sexual minority students seek counselling services at a higher rate than heterosexual students (Dunbar et al., 2017; Oswalt et al., 2019). Though this may appear in opposition to our findings, it is possible that sexual minority students are more likely to seek support for mental health that directly attempts to address symptoms, as opposed to seeking support that is disability or financially related. Our research team similarly discussed that the mental health challenges of sexual minority students may be attributed in different ways, both by service providers and potentially by students themselves, to involve stressors related to sexuality,

and thus to be less likely to be diagnosed or thought of as a disability, and thus viewed as less appropriate to be receiving services through CAL or mental health-related funding. This is problematic, as it suggests that sexual minority students have the potential to be excluded from important services that support students *alongside* their mental health challenges, instead being directed to or selecting solely services that work to disappear mental health challenges. A colleague who is a sexual minority and has mental health challenges expressed another possibility similar to that of students who chose not to report bias and harassment (Weise et al., 2021): that sexual minority students may assume that institutional services will not be supportive, and thus do not seek them out. A third possibility is that there are information barriers specific to sexual orientation. For example, one study found that within university library services sexual minority students report information barriers specific to their sexuality (Stewart & Kendrick, 2019). It is possible that the practical support information that exists does not adequately meet the information needs of this population, leading to a greater impact of barriers in this area for this population.

Financial Barriers. I ran the usual hierarchical regression analysis predicting financial barriers (see Table 17). The second step improved fit,  $\Delta R^2 = .17$ , F(5, 246) = 11.72 p < .001, and mental health functioning and financial stress were significant unique predictors of impact of financial barriers.

Table 17

Regression results using Financial Barriers

<i>b</i> [95% CI]	p	β	$sr^2$	Fit
-0.06 [-0.08, -0.04]	<.001	33	.11	$R^2 = .11$ $p < .001$
-0.03 [-0.05, -0.01]	.002	19	.03	
0.69 [-0.21, 1.59]	.134	.09	.006	
0.25 [-0.50, 1.01]	.512	.04	.001	
0.08 [-0.51, 0.66]	.795	.02	<.001	
1.13 [0.80, 1.45]	<.001	.40	.13	
0.35 [-0.31, 1.02]	.299	.06	.003	$R^2 = .27$
	-0.06 [-0.08, -0.04] -0.03 [-0.05, -0.01] 0.69 [-0.21, 1.59] 0.25 [-0.50, 1.01] 0.08 [-0.51, 0.66] 1.13 [0.80, 1.45]	-0.06 [-0.08, -0.04] <.001 -0.03 [-0.05, -0.01] .002 0.69 [-0.21, 1.59] .134 0.25 [-0.50, 1.01] .512 0.08 [-0.51, 0.66] .795 1.13 [0.80, 1.45] <.001	-0.06 [-0.08, -0.04] <.00133  -0.03 [-0.05, -0.01] .00219  0.69 [-0.21, 1.59] .134 .09  0.25 [-0.50, 1.01] .512 .04  0.08 [-0.51, 0.66] .795 .02  1.13 [0.80, 1.45] <.001 .40	-0.06 [-0.08, -0.04]

Learning Barriers. The usual regression (Table 18) revealed that adding demographic variables improving model fit,  $\Delta R^2 = .04$ , F(3, 251) = 3.68 p = .01. Financial stress and physical disability status were uniquely related to learning barriers, such that greater financial strain and having a physical disability were related to greater impact of learning barriers.

 Table 18

 Regression results using Learning Barriers

Predictor	<i>b</i> [95% CI]	p	β	$sr^2$	Fit
Step 1  Mental health functioning	-0.07 [-0.084, -0.048]	<.001	42	.17	$R^2 = .17$ $p < .001$
Step 2					
Mental health functioning	-0.06 [-0.075, -0.038]	<.001	36	.10	
Sexual minority status	0.15 [-0.38, 0.68]	.583	.03	<.001	
Financial stress	0.35 [0.047, 0.66]	.024	.16	.02	
Physical disability status	0.71 [0.085, 1.33]	.026	.13	.02	
Ĭ					$R^2 = .20$

There is ample evidence that students with disabilities, whether they be physical or mental health-related, are not well-served by current university instruction, and experience barriers related to inflexibility of assignments or exams and incompatibility in the format or method of instruction and students' needs (Fleming et al., 2017; Majoko, 2018; Vickerman & Blundell, 2010). Here, it is possible that having physical disability co-occurring with mental health challenges further impacts the number and type learning needs a student has that differ from mainstream instruction, and thus, as our results showed, learning barriers are exacerbated.

*Inappropriate Mental Health Services.* Results of the usual regression (see Table 19) revealed that the addition of relevant demographic variables significantly improved model fit,

 $\Delta R^2 = .13$ , F(3, 263) = 13.35 p < .001. Racial minority status was the only unique predictor of inappropriate mental health services impact,  $\beta = .34$ , p < .001, such that being a racial minority was related to greater impact. It is worth noting that mental health functioning was not a significant predictor in this final model, unlike in previous regressions.

Table 19

Regression results using Inappropriate Mental Health Services

<i>b</i> [95% CI]	p	β	$sr^2$	Fit
-0.01 [-0.014, -0.001]	.034	13	.02	$R^2 = .02$ $p = .034$
-0.01 [-0.011, 0.002]	.171	08	.006	
0.69 [0.46, 0.93]	<.001	.34	.11	
0.22 [-0.006, 0.44]	.057	.11	.01	
0.09 [-0.14, 0.32]	.426	.05	.002	$R^2 = .15$
	-0.01 [-0.014, -0.001] -0.01 [-0.011, 0.002] 0.69 [0.46, 0.93] 0.22 [-0.006, 0.44]	-0.01 [-0.014, -0.001] .034 -0.01 [-0.011, 0.002] .171 0.69 [0.46, 0.93] <.001 0.22 [-0.006, 0.44] .057	-0.01 [-0.014, -0.001] .03413  -0.01 [-0.011, 0.002] .17108  0.69 [0.46, 0.93] <.001 .34  0.22 [-0.006, 0.44] .057 .11	-0.01 [-0.014, -0.001] .03413 .02 -0.01 [-0.011, 0.002] .17108 .006 0.69 [0.46, 0.93] <.001 .34 .11 0.22 [-0.006, 0.44] .057 .11 .01

Note. A significant b-weight indicates the beta-weight and semi-partial correlation are also significant. b represents unstandardized regression weights; beta indicates the standardized regression weights;  $sr^2$  represents the semi-partial correlation squared.

The dimension of inappropriate mental health services contained two items: 1) lack of mental health care that is appropriate to one's cultural background, and 2) feeling pressured into accessing services one would not otherwise access. In terms of mental health care appropriate to

cultural background, there is ample evidence of disparities in mental health care between racial minority and White individuals, with racial minority individuals citing reasons such as mistrust of providers, limited cultural sensitivity, and experiences of racism as important determinants of whether help is sought and viewed as helpful (Busby et al., 2021; Giamos et al., 2017; Nwokoroku et al., 2022; Rabiee & Smith, 2014). Our team, as well as one previous study (Rabiee & Smith, 2014), discussed the intersection of racialization and religion as potentially exacerbating feelings of disconnection from mental health services, which are largely secular. Interestingly, one study found that sexual minority youth of colour were more likely to seek mental health services when living in areas with both lower homophobia and lower anti-Black racism (Roulston et al., 2022). Thus, barriers related to mental health care appear linked to environmental realities of discrimination. Further, a content analysis of university counselling websites specifically found greater presence of affirmations for sexual and gender diversity as opposed to diversity related to race and ethnicity (Mosley et al., 2019). This may further render racial minority students with mental health challenges invisible, and implicitly send the message that mental health services are not able to meet their needs.

The other item within the inappropriate mental health care dimension pertained to coercion into services. It has been established that racial minority groups are more likely to be offered medication as opposed to therapy, and are more likely to be coerced into treatment than White individuals (McKenzie & Bhui, 2007). Further, racial minorities are also more likely to have experience with criminal justice, child welfare, and immigration systems which may involve direct coercion into mental health care under threat of punishment (Joseph, 2019; Pon et al., 2011; Primm et al., 2005). Such experiences may influence perceptions of mental health care as coercive, whether experienced directly or related to intergenerational legacy. A racial minority

member of our research team discussed their experience of accepting what White service providers recommend because of internalized feelings of inferiority that dictated White authority figures must know best, thus describing a more subtle form of coercion that can occur. Our team as a whole discussed the potential for service providers to have more paternalistic attitudes towards racial minority students, perhaps pushing these students moreso in a particular direction of service access without engaging in as much information gathering and collaboration as they may otherwise. Thus, there are a variety of ways in which increased coercion may be experienced by racial minority students.

Culture of Self-Advocacy. This time, the second step of the usual regression (see Table 20) significantly improved model fit,  $\Delta R^2 = .09$ , F(4, 247) = 7.53 p < .001, and there were several unique predictors in the second step, including mental health functioning, being of sexual minority identity, reporting greater financial strain, and having a physical disability.

 Table 20

 Regression results using Culture of Self-Advocacy

Predictor	<i>b</i> [95%CI]	p	β	$sr^2$	Fit
Step 1 Mental health functioning	-0.04 [-0.046, -0.026]	<.001	40	.16	$R^2 = .16$ p < .001
Step 2  Mental health functioning	-0.027 [-0.037, -0.016]	<.001	30	.07	
Gender minority status	0.04 [-0.45, 0.52]	.885	.01	<.01	
Sexual minority status	0.42 [0.10, 0.74]	.010	.16	.02	
Financial stress	0.24 [0.059, 0.41]	.009	.15	.02	
Physical disability status	0.56 [0.20, 0.91]	.002	.18	.03	$R^2 = .24$

The unique role of physical disability in the experience of self-advocacy barriers appeared logical to our team, as having co-occurring mental health challenges and physical disability would likely necessitate greater engagement with a greater number of services that require self-advocacy, thus being both more burdensome to participants and increasing likelihood of encountering barriers along the way. A colleague with lived experience of physical disability and mental health challenges similarly affirmed that the segregation of services between mental health challenges and physical disability further exacerbates these barriers, as the presence of both often involves learning and navigating separate systems and different

professionals. Indeed, past research has found that there is an impact of the extra time burden for students who require involvement from multiple types of services in terms of the effort to coordinate appointments and connect with multiple providers, while managing schoolwork (Hong, 2015). Self-advocacy itself often requires students to utilize the very same skills for which they may be seeking accommodation, and thus it is logical that self-advocacy disadvantages both those with physical disability and those with more impactful mental health challenges (Bruce & Aywlard, 2021).

For sexual minority students, there are a range of unique barriers including experiencing homophobia and potential social isolation from other sexual minority students (Alessi et al., 2017). Further, in healthcare among the general population, sexual minority individuals have described an extra layer of advocacy required for care that is appropriate to their sexual orientation (Smith & Turell, 2017), suggesting that sexual minority students may have to engage in more or different types of self-advocacy than heterosexual students. Among our research team, those who identified as belonging to a sexual minority and having mental health challenges reflected that, for many university students, they are perhaps at the start of learning how to explore and assert their sexuality, and thus may prioritize navigating as a sexual minority over mental health-related concerns. Our team also discussed a potential desire among sexual minority students to not be further segregated; if students already feel segregated based on sexuality, they may not wish to further segregate themselves due to their mental health, and thus struggle with self-advocacy. Thus, the stress and extra navigation associated with being a sexual minority may leave less time and resources available for self-advocacy related to mental health.

*CAL Disclosure-Related Barriers.* Results of the usual regression (see Table 21) demonstrated that the addition of correlated demographic predictors did not improve model fit,

 $\Delta R^2 = .02$ , F(1, 98) = 2.30 p = .13. Only mental health functioning remained a significant predictor in the second step.

 Table 21

 Regression results using CAL Disclosure-Related Barriers

Predictor	<i>b</i> [95% CI]	p	β	$sr^2$	Fit
Step 1  Mental health functioning	-0.08 [-0.13, -0.02]	.007	27	.07	$R^2 = .07$ $p = .007$
Step 2  Mental health functioning Financial stress	-0.006 [-0.12, 0.0002] 0.72 [-0.22, 1.66]	.050 .132	21 .16	.04	$R^2 = .09$

*Note.* A significant b-weight indicates the beta-weight and semi-partial correlation are also significant. b represents unstandardized regression weights; beta indicates the standardized regression weights;  $sr^2$  represents the semi-partial correlation squared.

CAL Administrative Barriers. Lastly, a similar hierarchical regression analysis was run to determine to what extent mental health functioning and correlated demographic variables predicted the impact of administrative barriers within CAL (see Table 22). Adding correlated demographic variables in the second step did not significantly improve model fit,  $\Delta R^2 = .06$ , F(2, 97) = 3.05, p = .052. None of the variables in the second step uniquely predicted the impact of administrative barriers within CAL.

 Table 22

 Regression results using CAL Administrative Barriers

Predictor	b [95% CI]	p	β	$sr^2$	Fit
Step 1  Mental health functioning	-0.07 [-0.12, -0.02]	.008	26	.07	$R^2 = .07$ $p = .008$
Step 2					
Mental health functioning	-0.05 [-0.11, 0.003]	.065	19	.03	
Financial stress	0.66 [-0.15, 2.77]	.079	.16	.02	
Physical disability status	1.31 [19, 1.51]	.126	.17	.03	
arsaomity status					$R^2 = .13$

### Summary of Results

In sum, I found that, in nearly all cases, adding demographic predictors significantly improved model fit over and above mental health functioning alone. Poorer self-reported mental health functioning was a consistent predictor of experiencing a greater impact of barriers, uniquely predicting experience of barriers in all areas except inappropriate mental health services and CAL administrative barriers. Financial stress uniquely predicted greater impact of six different domains of barriers, including stigma and negative interpersonal interactions, service navigation barriers, practical support knowledge barriers, financial barriers, learning barriers, and self-advocacy related barriers. Physical disability status uniquely predicted greater impact of three different domains of barriers, including service navigation barriers, learning barriers, and

self-advocacy related barriers. Sexual minority status uniquely predicted impact of barriers related to practical support knowledge and self-advocacy. Racial minority status was a unique predictor of the impact of inappropriate mental health services, and was the only significant predictor of the impact of this set of barriers. Education level uniquely predicted barriers related to mental health services.

It is also worth noting that lower mental health functioning consistently predicted greater impact of barriers. Although our team was expecting this, this finding is worth further reflection, as it means that those most in need of supports in university have the greatest struggle in accessing those supports. Interestingly, we found little research that assesses how differential levels in functional impact of mental health relate to service use and outcomes, and thus our finding clearly warrants further investigation. There is evidence that students who report greater impact of their mental health on academics report greater help-seeking (Cage et al., 2020), and that among the general population, greater subjective distress, work, and social impairment predict greater help-seeking (Angst et al., 2010). These results suggest that our finding of greater impact of barriers may be related to the amount of service use; if individuals experiencing greater impacts of their mental health functioning seek a greater number of services, then this greater amount of services represents increased exposure to the potential experience of barriers.

However, the opposite could also be argued. For example, there is some evidence that those with greater severity of depression are less likely to seek treatment when internalized stigma is also high (Fox et al., 2018). Here, it is possible that a greater impact of barriers is experienced because the structures designed to support individuals with mental health challenges are not accessible for those experiencing greater impact of mental health challenges, and thus are not accessed. Members of our team similarly commented on the possibility that those with more

impactful mental health challenges may also engage in more internalized invalidation that their experience is not "bad enough" or "worthy" of support, and that this was a barrier to accessing supports. Whereas such barriers could be argued to be internal and individual barriers, these barriers have a structural dimension: if mental health symptoms interfere with individual ability to access supports and services, then it suggests that there are design features of services that may not be accessible for individuals with mental health challenges. In this way, more impactful mental health challenges may at times lead to less help-seeking, and thus greater impact of barriers due to feeling shut out or turned away from services.

There is a third potential explanation for this finding. Among investigations with individuals with severe mental illness, there is evidence of lower quality of healthcare provision and worse objective life conditions among this population compared to those with either no or mild to moderate mental illness (Evans et al., 2007; Lawrence & Kisely, 2010). Although such a measure is not directly analogous as severe mental illness is grouped by diagnosis rather than functional impact, these results suggest that greater impact of barriers may not be due to mere greater exposure to various services, but due to services that are of lower quality and less accessible to individuals with more impactful forms of mental health challenges due, in part, to poorer objective life conditions that can exist among this group. Research team members reflected that university services in particular may not be set up to provide adequate service to individuals with more impactful mental health challenges (e.g., due to the training of available personnel, limited availability of support), instead being best equipped to serve individuals with more mild and temporary mental health challenges. Thus, greater impact of barriers could also be due not to the amount of help-seeking, but to differences in the quality of support available to those reporting more impactful mental health challenges.

Our findings also highlighted a strong link between financial strain and experiencing more structural barriers related to mental health. Certainly, it has been identified that finances are a common barrier among students with mental health challenges, both due the potential of financial strain to create or exacerbate poor mental health, but also due to increased financial demands that can occur alongside mental health challenges (e.g., cost of prescription medications, medical documentation, and therapy; Megivern et al., 2003). Here, students who experience more financial strain would undoubtedly be more greatly impacted by their ability to access these services, as we found in the current study, and indeed, cost has been noted as the biggest predictor of help-seeking among college students in the United States (Marsh & Wilcoxon, 2015; Miranda et al., 2015). It has also been found that students who work during academics, which may represent students who experience greater financial strain, are less likely to reach out to services (Oswalt et al., 2019), and that students with learning disabilities from lower socioeconomic status backgrounds struggle more with service navigation (Waterfield & Whelan, 2017), aligning with our results that a number of barriers are exacerbated when financial strain is present. Our research team similarly expressed that the extra time and responsibility burden associated with inadequate finances impacts individuals with mental health challenges' opportunity to spend time on ensuring their mental health is supported in various ways during university. Thus, it is possible that, in our study, participants reported greater impact of barriers associated with service navigation, practical support knowledge, learning barriers, and selfadvocacy because they have less time and resources to spend on identifying and accessing relevant services and on academics, as time is spent instead working or engaged in other efforts to manage overall financial strain.

### **Qualitative Results**

A qualitative content analysis was undertaken to: 1) determine structural barriers that were missed in initial questionnaire development, 2) determine supportive services or strategies students with mental health challenges make use of, and 3) explore participant ideas for potential solutions to these barriers. Upon analyzing the data, I noted that participants often shared more specific examples, explanation, or reinforcement of the importance of certain barriers already existing on the questionnaire. This portion of the data is not shared here, as the focus of this analysis was to explore new or missing ideas from the quantitative portion of our research.

### Additional Barriers

Through participant qualitative responses, I identified additional barriers that were not present in our questionnaire. In Table 23, I provide proposed items to be added to the measurement of structural barriers at university in future research based on this qualitative analysis. In Table 23, new barriers are grouped by the sections of the questionnaire in which they would appear (i.e., barriers encountered within CAL would be presented alongside other barriers encountered in CAL). When looking across these identified barriers, I identified several themes:

1) barriers related to identity or social location, 2) barriers related to previously un-identified service limitations, and 3) barriers related to university culture. The frequency of comments related to each new barrier is not reported, as the aim of this portion of the analysis was to identify gaps in our knowledge, and thus this analysis focused on whether new substantive content was provided by participant data, rather than how frequently such content arose.

**Barriers related to identity or social location.** We identified several new barriers related to identity or social location. In several cases, these barriers were related to the intersectionality of being a student with mental health challenges *and* being marginalized for

other aspects of identity. One participant wrote, "CAL also displayed my legal name (which I do not use and makes it fairly obvious I am trans) on... auto generated forms you send to professors about your accommodations." This participant thus highlights that accessing CAL services as a transgender person may require that such individuals "out" themselves to receive necessary supports. Several participants also highlighted the overarching role of financial strain, stating that it is not only barriers related to financial accessibility of particular services, but overall financial strain that shapes experiences of university and of mental health. As one participant wrote, "Financial crisis. You cannot eat if you don't work and you cannot study if you work hard." Beyond this, participants also wrote about barriers due to various prejudices in university, such as racism, sexism, homophobia, and ableism.

Several participants also wrote about barriers experienced due to their experience of their own mental health. For example, participants wrote about internalized invalidation as a barrier to accessing support, as one participant stated, "I have not sought any accommodations... largely because of my internalized idea that I don't deserve any." Others wrote about how the exact areas for which they were seeking support (e.g., anxiety, lack of motivation) made it challenging to access supports. One participant wrote that they had not found any helpful supports, "because I am too afraid to use the ones available." Another wrote "It is hard for me to advocate for my own mental health, as depression causes me to lack any and all motivation to do anything but the minimum." In this way, barriers could be seen in the ways in which support services do not account for accessibility to the population of interest in the way they are designed.

Additional un-identified service limitations. Participant responses identified several service limitations which acted as structural barriers beyond what we originally identified in our questionnaire. These included turnover of service providers, being provided insufficient or

inaccurate information, challenges with both initial and ongoing access to services, and lack of general practitioner services. Many participants commented about the lack of quality of available information, as one participant stated a barrier for them was "unorganized websites with vague instructions on how to access information," and another stated "information is not up to date." Others commented on specific service limitations, as one participant wrote an additional barrier they experienced was "long wait time between appointments... the wait times make me very anxious."

Barriers related to university culture. Participants highlighted productivity culture, or expectations that academics were prioritized above all other aspects of life including mental health, as a barrier. One participant described, "Expectation of grinding and working long yours beyond your limits. I see people in my program routinely work on the weekends, or stay on campus to work from 9 am to 10 pm... this culture endangers my already fragile mental and physical health and makes chronic illnesses worse. Everyone does it, though, so you feel like you need to do it to keep up." Another commented, "It is a culture that is assumed to be stressful yet there is a lack of [advice] for how to manage the stress."

Proposed Item Additions for Future Structural Barriers Questionnaire Based on Qualitative

Survey Responses	
Centre for Accessible Learning	Being negatively impacted by the requirement that CAL display student's legal name on documents.
Item Additions	Lack of ongoing relationships with CAL staff due to re-referrals or high staff turnover.
	Not being provided sufficient information about potential available accommodations.
Information Item Additions	Being able to access information related to university services (e.g., mental health, health, CAL), but the information is inaccurate or out-of-date.
Health and Mental Health Services Item Additions	Challenges getting initially connected to health and mental health service providers (e.g., over-burdened phone lines, requirements to disclose personal information before appointment).
	Lack of general practitioner services (i.e., family doctor) available that meets your needs.
	The length and/or frequency of appointments with health or mental health service providers is inadequate to meet your needs.
Financial Item Additions	Financial stress and obligations impacting time and resources available to access support for mental health.
University Culture Item Additions	Pressure to prioritize academics and productivity at the cost of personal mental health.
	Encountering prejudice (e.g., racism, sexism, homophobia, transphobia, ableism) in academics, health, or mental health services.
	Challenges accessing services and supports because of your mental health symptoms (e.g., lack of motivation, anxiety about reaching out).
	Challenges accessing services and supports because you do not believe you are deserving of support (e.g., beliefs your experience is not bad enough, beliefs you are exaggerating your symptoms).

## Strategies and Supports

Table 23

Strategies and supports that students described using within university were diverse, and included, 1) formal supports targeted at mental health, 2) broader supports offered by the university, and 3) personal strategies. Although frequencies of comments were tracked,

frequency should not be over-interpreted to be equated with the actual supportiveness of different services (e.g., 27 comments of CAL being supportive versus 47 comments of health and mental health services being supportive should not lead to interpretation that health and mental health services are superior to CAL services). However, it is worth noting that, by far, the most common strategies for success in university among students with mental health challenges did not relate to any service, but rather were discussed in terms of individual efforts, whether it be personal relationships, individual academic strategies, or individual mental health strategies. Though still worth interpreting with caution, such a broad discrepancy points to the potential that students with mental health challenges most commonly rely on themselves and their personal relationships as opposed to formal support services.

Formal Supports Targeted at Mental Health. Participants commented on the utility of formal support services which explicitly aim to assist those with mental health challenges. Participants commented on the helpfulness of CAL services (27 comments) and mental health and health services (47 comments), aligning with previous findings of the importance of these services (Hartrey et al., 2017; Lindsay et al., 2018; Magnus & Tøssebro, 2014). These services were not necessarily limited to within the university. For example, some participants reflected on the helpfulness of accessing mental health services within the community. Within these services, participants shared experiences of helpful interactions and relationships, and the supportive role of interventions such as therapy, medication, and accommodation. For example, one participant wrote "The counsellor for the law school was particularly helpful in giving me clear direction to access a psychiatrist through the school." Another wrote, "Getting accommodations was very straightforward and helped with both my class experience and my mental health."

Broader University Supports. Participants also discussed supports at the University of Victoria that were important for their experience at university as a student with mental health challenges. Sixteen comments were made about a diverse range of university supports that are not directly related to mental health, including library support, formal peer support, the First People's House, the Study Solutions Office, academic advisors, varsity support, the Office of Student Life Coordinator, and accessing priority housing. For example, one participant wrote, "I also spend a lot of time in the First People's House at UVic which provides a culturally safe place for me to study and socialize. There are many other supports in this building that I access which has helped me succeed as a student."

Twenty-seven participants also commented about the role of professors in supporting students. Participants described that professors were helpful because they could be communicated with directly and contribute to timely flexibility and problem-solving, whereas other services may be slower to respond. One participant wrote, "Professors are usually total gems as well, I've never encountered a faculty member who didn't do what they could to help." Another wrote that a successful strategy for them was "introducing myself and being known personally by my teachers."

These broader examples of support outside of what is typically considered "mental health" supports could be an example of what Townley and colleagues (2013) discovered about the role of distal relationships: that these informal, casual, and at times more distant relationships with members of the community uniquely predict community integration even after accounting for more traditional support networks. These researchers noted that such distal relationships often provide more tangible support, as is similarly implied by the types of services listed by students. A few participants also discussed the supportive role of the First People's House,

emphasizing the importance of culturally safe spaces. Importantly, these results suggest that the role of supporting students with mental health challenges is not limited to those engaged in what is thought of as mental health services: everyone in the university community has an active role in improving (or worsening) the experience of students with mental health challenges in university.

Such a distributed role aligns with calls for interventions that promote collective resilience of communities (Walker et al., 2017). Such strategies seek to foster bonds, both between individuals and between individuals and institutions, that hold communities together and that provide support and protection throughout one's experience, including in times of extreme stress (Walker et al., 2017). Propositions for these types of resilience-promoting spaces include those that were shared by participants, including libraries, sporting activities, and cultural and religious spaces. The idea here is that such community spaces will offer ongoing support and, at times, places where individuals can continue to engage in meaningful work and activities regardless of how their mental health fluctuates over time, and thus represent an important source of stable connection to community.

Personal Strategies. Most often, participants shared personal strategies they found supportive of their experience at university. These included academic strategies (23 comments), personal relationships (43 comments), individual mental health strategies (44 comments), and individual practical strategies (12 comments). Personal academic strategies were largely discussed as work behaviours that participants engaged in, as well as exercising control to create an academic experience that met their needs. For example, one participant wrote a successful strategy for them was "constant planning and updating calendars to keep up with work." Another wrote that "taking less classes, and extending my graduation timeline" was essential for them.

The implication of discussing personal academic strategies was that one's ability to manage academics successfully is both a component of managing mental health, and a potential determinant of mental health in that effective management of academics can reduce stress.

Many participants also commented on the value of personal relationships as a key source of support. The importance of healthy relationships was emphasized, and relationships were discussed as places where advice could be sought and where participants could be honest about their needs. For example, one participant wrote "good friends who are willing to help you through everything even when the staff or peer supports are not available," and another wrote "being open with my loved ones. With every hurdle I dealt with, it was made significantly easier by talking it out with my support system." Participants referred to friends, family, partners, and roommates as important sources of emotional support and encouragement and practical support for help-seeking.

Participants also discussed engaging in concrete behaviours and fostering certain attitudes and beliefs about mental health that facilitated their well-being. In terms of behaviours, participants shared strategies such as meditating, adequate sleep, eating healthy, and engaging in particular hobbies as supportive. For example, one participant shared a strategy of "doing something totally different before bed to relax and turn off my brain." Participants also shared certain beliefs they attempted to foster in themselves to support their mental health. For example, one participant wrote "getting outside of my head and think[ing] about the fact that there are others that may be feeling the same way I do." Several participants also commented about the role specifically of prioritizing their mental health, as one participant wrote "making sure I leave time in the day to perform acts of self-care and have moments to myself."

Finally, a smaller number of individuals discussed overall practical support strategies that helped them in various domains, including academically, but also in navigating and accessing other formal supports for mental health. These included participants being their own advocate through behaviors such as doing their own research, asking for help, and learning to be selective about disclosure of their experience. For example, one participant wrote a strategy that had worked for them was "doing my own research, and quoting the official website if the person doesn't understand." Another wrote, "asking questions even if they're redundant, to anyone and everyone who I think might have a good answer. It always feels a little embarrassing but it also always helps."

The strategies our participants discussed appear common, as previous qualitative findings have established common methods of student coping including effectively managing time, limiting responsibilities, maintaining a strong social support network, and self-managing mental health (Hartley, 2010; Kain et al., 2019; Knis-Matthews et al., 2007; Kranke et al., 2013; Lindsay et al., 2018). This points to the importance of acknowledging that, although this study is designed to focus on structural barriers and supports, such a focus is not meant to diminish the immense personal efforts that are undertaken by students to persist in university (Price-Robertson, Manderson, & Duff, 2017; Price-Robertson, Obradovic, & Morgan, 2017). This also aligns with findings by Reid and Poole (2013), that far from university students with mental health challenges being "needy," these students are often highly resourceful and full of a wealth of knowledge of about how to support themselves in the absence of greater institutional support.

#### **Solutions**

A summary of ideas for solutions from participants is provided in Table 24.

Unsurprisingly, solutions were often tied closely to what was identified as impactful barriers. For

example, academic solutions of greater flexibility embedded into instruction and positive cultural shifts were directly related to the rigidity and culture of over-work noted as impactful within barriers. One participant proposed a solution of, "make it clear to students that their mental health comes first – all of the professors and university staff were also students once but they seem to have little to no compassion surrounding these things."

Solutions within various domains (e.g., CAL, information-related, health and mental health, peer support) often involved improving the availability and quality of existing resources and ensuring adequate support for navigating available services. For example, one participant wrote, "Have a better vetting process for what kind of people are hired at UVic to provide mental health services for students." Suggestions for streamlining access processes were discussed among different services such as CAL, health, and mental health services. For example, one participant proposed a CAL-specific solution, "when students are registering for school there could be a section that you also fill out with the rest of your paperwork so you're automatically being considered before the year even starts... then students would understand the program better and it could potentially become more normalized."

Participants also provided specific ideas for financial supports that more closely reflected the reality of students with mental health challenges' needs. Overall, solutions provided by participants were diverse, and specific ideas for solutions were often only aligned among small numbers of participants. Thus, these initially generated solutions represent a first step of possible solutions to barriers identified by participants with mental health challenges.

**Table 24**Summary of Proposed Solutions from Qualitative data

Centre for Accessible Learning Solutions

- Hire more CAL advisors
- Provide high quality training for CAL advisors
- Ensure capacity for regular meetings with students to assess effectiveness of accommodations

- Develop easier communication channels between students and CAL advisors
- Ensure information about CAL is provided to all students
- Provide specific orientation information when students enroll in CAL
- Develop greater flexibility in booking process related to accommodations (e.g., exam rooms)
- Provide independent advocate to help with application and mediation of concerns
- Expand options for accommodations

### Information-Related Solutions

- Ensure information is well-distributed and accessible to students (e.g., through BrightSpace, information sessions, visible postings around campus)
- Create information tailored to diverse information needs (e.g., information about how to access services, about the cost of services, on and off campus resources, for students who move from out of province)
- Educate the broader University of Victoria community (e.g., about mental health and substance use, racism, LGBTQ+ issues)

## Health and Mental Health Services Solutions

- Develop greater availability of services (i.e., hours of operation, frequency of appointments)
- Expand services (e.g., walk-in services, ongoing support, specific types of mental health services, support for finding off-campus counsellors)
- Provide dedicated advocates to help with navigating and accessing health and mental health services
- Develop simplified processes for initial service access (e.g., online booking, appointment reminders)
- Hire providers who are competent, understanding, and have adequate workplace support
- Improve financial accessibility of services (e.g., improving health care plan support for counselling and psychiatric medications)

# Other Services Solutions

• Expand supports for international students

# Academic Solutions

- Increase flexibility (e.g., hybrid learning, flexible due dates, multiple options for methods of evaluation)
- Work towards cultural shifts (e.g., decolonizing education, reducing competitive culture, reducing productivity culture)

## Financial Solutions

- Provide financial aid for students who take longer to complete degree due to mental health challenges
- Provide personalized student loan assessments and applications
- Provide more affordable schooling

## Leave-Related Solutions

- Eliminate costs and financial penalties associated with leave (e.g., tuition re-imbursement, eliminating re-registration fees)
- Eliminate academic penalties associated with leave

- Embed accommodation processes in process of leave (e.g., support with paperwork)
- Reduce stigma associated with leave

**Peer Solutions** 

- Expand peer support services (e.g., social events, peer counselling)
- Improve outreach of existing peer support services
- Develop more informal campus spaces for peer connection

Despite this, it is notable that student solutions often corresponded closely to those which have been recommended in the literature. An emphasis on high quality and accessible information distributed in multiple ways about the services and rights of students with mental health challenges was discussed as essential both by our participants and within research on university disability services (Banerjee et al., 2020), counseling services (Gibbons et al., 2019), and within a broad review and recommendations for university students with mental health challenges (Mowbray et al., 2006). Similarly, the necessity of expanding mental health services in terms of the type of support available, hours of access, quality of services, and financial availability of services has also been noted (Mowbray et al., 2006; National Council on Disability, 2017). Expansion of peer support has also been recommended (Mowbray et al., 2006; National Council on Disability, 2017). The presence of such similar solutions across various geographic contexts and, in the case of Mowbray and colleagues (2006), across a broad time span, highlights that both barriers and potential solutions have dimensions that are common among Western institutions. At the same time, several solutions discussed by participants (e.g., developing easier communication channels between students and CAL advisors, developing simplified processes for initial service access) appear unique to this study, and may speak to access issues specific to the University of Victoria. Due to the broad nature of this study, we also captured potential solutions for domains that have not been discussed in the literature, including financial solutions and leave-related solutions. Further, our participants were also unique in

highlighting the necessity for underlying cultural changes (e.g., addressing productivity culture) as important for improving university experiences.

### **Summative Discussion: Structural Stigma and Its Implications**

The current study identified a range of important information about structural barriers in university for students with mental health challenges. First, we identified the top 10 most impactful barriers as rated by our participants, which included learning barriers, self-advocacy related barriers, mental health services barriers, disclosure-related barriers and administrative barriers related to the process of taking a leave. We also identified the various dimensions of structural barriers that students with mental health challenges faced, and identified that both mental health functioning and a range of demographic factors moderate the impact of these barriers. Qualitative results were analyzed to determine any areas of structural barriers that were missed within our questionnaire, and allowed participants to provide potential solutions to structural barriers.

To sum, though focusing on structural barriers, we found evidence of stigma across three intersecting levels: structural, public, and internalized (Charles & Bentley, 2016; Hatzenbuehler, 2016; Livingston, 2013). It is worth noting that, on most our subscales of structural barriers, responses were approximately normally distributed. Thus, being impacted by these barriers was not an isolated experience for a few, but something that appeared quite commonplace. Our survey was designed to capture structural stigma, but we also established public stigma through a stigma/negative interpersonal interactions subscale which captured being exposed to a range of negative beliefs and stereotypes of others in university. Although internalized stigma was not originally a part of our questionnaire, a range of qualitative comments conveyed internalized stigma, as participants discussed their lack of adequate support as resulting from personal

failings or their own lack of worthiness. Such attitudes can lead individuals to believe they should be able to participate and succeed in communities when in fact there are myriad structural barriers that would make it challenging to do so (Frederick et al., 2017).

These three layers of stigma are not independent. When reflecting on our questionnaire and established subscales, it is easy to see how barriers related to issues such as service navigation and learning environments, if viewed by the general public through a psychocentric lens, could perpetuate negative beliefs and stereotypes of individuals with mental health challenges such as that such students lack capacity or potential. Such views in turn could feed back to those in positions of power which, when influenced by such views, may lack urgency toward fixing or even understanding the ways in which individuals with mental health challenges are impacted by ongoing stigmatizing policies and procedures. This institutional response and messaging, in turn, could foster negative internalized beliefs among individuals with mental health challenges themselves. In this way, the structural stigma observed should not be seen as purposeless, but rather an ongoing set of practices that occurs at multiple levels to keep individuals with mental health challenges out of success in higher education, and to keep current systems in tact (Tyler & Slater, 2018).

Our analysis further demonstrated that among a sample of participants with mental health challenges, experience of barriers was inequitably distributed in relation to a broad range of demographic factors. This reinforces the importance of calls to focus on how demographics such as race, gender, and socioeconomic status intersect with experiences of disability and to consider this within efforts to alleviate inequality (Liasidou, 2013). Our analysis aligns with evidence that disparities related to access to support services for mental health are in part determined by social, environmental, and economic structures (Pearson et al., 2015). In our analysis, we found

evidence of certain barriers that are exacerbated among individuals of particular social locations, for example, more financially strained students reported greater impact of barriers than less financially strained students across a variety of domains, including service navigation, learning barriers, and self-advocacy barriers. Alternatively, we also found evidence of barriers that fundamentally differed among participants of certain backgrounds and experiences, for example, being a racial minority was the only significant predictor of reported impact of coercive and culturally inappropriate mental health services. This aligns with findings that particular combinations of social location can cause barriers that may not be represented at all among individuals without the same combination of identities, rather than solely an "additive" effect where barriers may become more impactful as identities overlap (Mosley et al., 2019). Essentially, this finding suggests that a failure to adequately address structural barriers related to mental health not only excludes those with mental health challenges, but may disproportionately exclude and marginalize individuals who do not fit the "typical" university student in a variety of ways (e.g., straight, cis-gendered, White, upper-middle class). In this way, structural stigma related to mental health in education has the potential to perpetuate a number of social inequalities.

In light of both the pervasiveness of barriers and the ways in which such barriers have the potential to perpetuate ongoing inequalities, it is worth re-thinking anti-stigma efforts. As discussed previously, many anti-stigma efforts at the University of Victoria (and beyond) target public stigma or individual beliefs (e.g., Bell Let's Talk, 2022; University of Victoria, n.d.; Vynchke & Van Gorp, 2020). I have argued, however, that such beliefs are rooted in embedded institutional practice. Thus, these findings also have implications for anti-stigma work. For example, anti-stigma efforts could be engaged in ameliorating barriers that enable ongoing

exclusion and discrimination. In this way, a campaign focused on accessible educational practices or revising policies in such a way that does not require students to disclose intimate health details to receive support are both anti-stigma efforts. Evaluating such efforts for their ability to promote inclusion, belonging, and student success alongside a reduction in stigma would be a productive step forward.

#### Limitations and Future Directions

There are several limitations to the current study. First, participation was limited to current and former students from the University of Victoria. Although this aligns with our aim to collect locally specific information, it is unknown to what degree these results would generalize to other universities within and outside of Canada. Future researchers may wish to investigate across universities to see to what degree impact of barriers is universal versus unique to specific settings. Such investigations may fruitfully consider geographical location, differences in actual service availability by university, differences between public and private universities, and differences in the size of universities in experience of barriers. Our sample size was also insufficient to examine differences in barriers by department, though differences in departmental support was noted by participants in qualitative responses. Due to a number of characterological differences between departments in terms of culture, size of classes and programs, and type of learning and evaluation methods, it would be interesting to investigate barriers that may be unique to specific departments.

Although our overall sample size was sufficient to detect a variety of effects, our sample size for both students involved in CAL and students who had taken a leave were smaller, and thus we were not able to detect effects or, in the case of leave experiences, do the same types of analyses relating to these barriers. Future research may wish to recruit samples with these

experiences to ascertain in greater depth the impact and nature of these barriers. Our sample was also predominantly women. We did not detect differences in impact of barriers between men and women, but a larger sample of men would be important to further investigate this. We did find differences between gender minority and cis-gendered students in impact of barriers, though our small sample of gender minority students was also small (n=32). Thus, future research should aim to recruit a more gender diverse sample.

We attempted to analyse the degree to which different demographic factors predicted experience of barriers. Though our results are a first step towards understanding the inequitable impact of barriers, further research to understand in depth the nature of these differences is needed. We examined a potential additive effect of demographic predictors in experience of barriers, to determine whether components of identity besides mental health challenges played a role in the experience of barriers. Future research may aim to incorporate intersectionality more explicitly by, for example, examining whether demographic factors moderate the relationship between mental health functioning and experience of barriers. Further, our analyses separated demographic factors from each other to look at impacts separately. Future research may wish to examine how impacts differ among individuals who are multiply marginalized.

Nuance also exists within the different demographics we focused on, such as, for example, racial minority students comprising individuals of different racial and ethnic backgrounds, Indigenous students, individuals who immigrated to Canada, international students, and racial minority individuals whose families have been in Canada for multiple generations.

Though being a racial minority itself clearly impacted the experience of barriers in a variety of ways, looking specifically at how these impacts may contrast based on various differences within this group would be important. Similarly, in terms of financial strain, it would be important to

further explore differences within this group, in terms of working versus non-working students, and to what degree students' social determinants of health needs are met (e.g., housing, food), to further explore the degree to which various components of financial strain play a role in the experience of barriers.

Further, our research focused on experiences of structural barriers within university. This was done to focus our research and provide an in-depth assessment of barriers at university, but it is worth noting that universities are embedded within communities. Although participants reported on their experience of structural barriers within university, it is entirely possible that they were experiencing structural barriers in other areas of life, such as healthcare, housing, and employment. Indeed, it is known that structural stigma exists in these realms for individuals with mental health challenges (Livingston, 2013). A more in-depth investigation of structural barriers that are experienced across various domains of life would be important for understanding how structural stigma is embedded in communities and impacts individuals across various domains of their lives.

Although our development of a questionnaire to measure structural barriers for university students with mental health challenges was an aim and a strength of this study, the limitations with developing a new questionnaire must be noted. Though we aimed for our questionnaire to have a strong basis in previous literature and lived experience, the aim of this study was not measure development, and thus the reliability and validity of the questionnaire were not explored in depth, but rather we focused on conducting preliminary analyses to support the specific aims of this study. Indeed, within this study participant qualitative responses identified further areas of importance. Further research and review would support the development of this questionnaire.

Qualitative responses were collected via an online survey. Although such a method allowed participants flexibility and anonymity to discuss what was important to them, most responses were, as is typical of online qualitative responses, brief. Thus, we were able to describe additional barriers, as well as supports and solutions, but the nature of this data did not allow for greater depth of analyses. Further, especially in the case of proposed solutions, specific ideas for solutions varied greatly between participants. Future research may wish to explore ideas for solutions to barriers in depth in interviews or focus group settings, as well as focused on a more narrow topic (e.g., solutions to improve accessibility of CAL specifically), in order to to allow participants to further discuss with each other and refine ideas for solutions.

Our investigation represents an initial step towards identifying and prioritizing barriers in university for students with mental health challenges. Future research should expand on these findings in several ways. First, it would be interesting to determine the degree to which perceptions of barriers are shared between students, faculty, and university staff, to determine whether any misalignment in priorities exists between these groups. It would also be interesting to discuss with various stakeholders what barriers exist to meaningfully improving systems to support students. For example, it is well-established that current methods of classroom instruction and evaluation disadvantage individuals with disability (e.g., Fleming et al., 2017; Majoko, 2018; Vickerman & Blundell, 2010), and, at UVic specifically, there are existing resources and supports to help instructors develop alternative methods of teaching and evaluation, at times aligned with universal design principles (Learning and Teaching Support and Innovation, University of Victoria, 2021). It would be interesting, then, to explore perspectives on why such resources are not utilized or implemented, and what other interventions or

incentives may be needed to support instructors to reduce learning-related barriers in their classrooms.

Our research also took place during the COVID-19 pandemic. Responses to this survey were collected between June and September of 2021. This was an important time period in the pandemic for the University of Victoria, as courses returned to in-person in September of 2021. Because participants were at different stages in their education, some may have only experienced online learning, whereas others may have experienced the shift from in-person to online learning. Regardless, given that our responses were collected towards the end of a lengthy period of online-only university programming, which began in March 2020 and ended in August 2021, it is likely that respondents were reflecting on their experiences of university during COVID-19 when completing the survey. University health services were also disrupted during this time, with many health and mental health services only providing virtual options for appointments. Thus, especially regarding the barriers that were rated as most impactful by students, it is unclear whether the impact of such barriers was related to education shifts related to COVID-19 or would remain as learning and service provision environments shift to in-person or hybrid models.

# Chapter 3: A World Café of Self-Advocacy Related Barriers

# Self-Advocacy as the Focus of Study 2

The intention of Study 1 was to provide a broad perspective of which barriers students with mental health challenges found impactful to guide a more narrow and in-depth focus for Study 2. We decided to focus Study 2 on a further exploration of the barriers that were identified as second and fourth most impactful by students with mental health challenges on average: 1) Expectation of being your own advocate in health or mental health services, and 2) Navigating health and mental health services without guidance. This means that we chose not to explore in further depth the top identified barrier, "Barriers related to 'typical' university evaluation (e.g., timed tests, strict academic schedules/due dates.)" This decision was made among our research team for several reasons.

First, we felt there are marked differences in awareness around these two issues. In terms of the barriers associated with typical university evaluation, much has been written about equity concerns related to certain forms of evaluation (Bensimon, 2005; Hanafin et al., 2007; Hobbs et al., 2021; Irwin & Hepplestone, 2012; Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013). Alternatively, the barriers associated with placing a burden of self-advocacy on students with mental health challenges are, to our knowledge, less widely discussed. Indeed, even within this project, the items in our survey related to self-advocacy were posed by members of the research team with lived experience; my review of the literature on barriers for students with mental health challenges did not identify self-advocacy as an issue. In fact, if one searches the literature for discussions of self-advocacy in higher education, one will find much literature suggesting that self-advocacy is a key skill to success and a skill to be trained (e.g., Daly-Cano et al., 2015, Vaccaro, & Newman, 2015; Kartovicky, 2020; White et al., 2014), without questioning what

might create the conditions for certain students to successfully advocate for themselves while others cannot (Roberts et al., 2016). Thus, a discussion of barriers related to self-advocacy would offer a much needed perspective and critique of existing assumptions.

Second, we also discussed as a research team the sense of our own power to understand and act on certain issues. When discussing typical university evaluation, we felt a collective powerlessness. Our role as students meant we did not necessarily feel we would have the knowledge or ability to advocate to university faculty and upper administration for a different approach to evaluation. We also identified several deeply rooted structural barriers that make change on evaluation methods slow or unlikely, including typically large class sizes that seem to necessitate certain types of evaluation (e.g., multiple choice tests), and a lack of time, resources, and incentive for instructors to learn about and invest in alternative forms of evaluation. When discussing self-advocacy, our sense of power was much different. Research team members could easily think of a wealth of experiences related to the topic of self-advocacy, whether it be their own attempts at self-advocacy, advocating on behalf of others, or having someone advocate for them, and compare and contrast helpful versus unhelpful experiences. Together, we discussed and analyzed those experiences and how change could be made, both through systemic change and through interpersonal changes in relationships between students and staff, and among students. Thus, through our own team dialogue, we determined that barriers related to selfadvocacy fostered richer dialogue and a greater sense of empowerment and inspiration than challenges related to university evaluation.

Finally, exploring barriers related to self-advocacy clearly aligns with the theoretical orientation of this dissertation. Psychocentrism presents within mental health care by conceptualizing distress as rooted within the individual (Rimke, 2016), it may present within

system navigation through self-advocacy narratives. In short, self-advocacy narratives individualize responsibility to receive support to the individual, and therefore conceptualize any issues encountered with access as rooted within the individual, as opposed to structural barriers and constraints. Such an approach both further stigmatizes individuals with mental health challenges by suggesting that those who do not receive support do so because of individual failing (e.g., lack of effort or willingness to change), and obfuscates the need for structural changes to better support individuals with mental health challenges. Thus, further exploration of self-advocacy would support our understanding of how reliance on self-advocacy fosters psychocentric narratives and ongoing structural stigma.

# **Self-Advocacy: A Brief Introduction and History**

As Study 2 of this dissertation focuses specifically on the concept of self-advocacy, I will provide a brief explanation of this concept's various definitions, uses, and history. The movement towards self-advocacy first occurred in the West within the disability rights movement in the 1960s and 1970s (Dowse, 2001; Oliver, 1990; Test et al., 2005; Traustadóttir, 2006). This movement was originally developed to assert disabled people's right to exercise power and agency in their own lives and play a role in their own decision-making (Dowse, 2001; Test et al., 2005; Traustadottir, 2006). This movement rejected the overreaching role of professionals in disabled people's lives, and asserted that professionals had too much power in guiding and deciding the course of disabled people's lives (Dowse, 2001; Test et al., 2005; Traustadottir, 2006).

Similar to how other terms from the disability rights movement, such as empowerment, were co-opted by service providers, self-advocacy has taken on a new meaning when used by institutions (Aspis, 2002). Rather than referring, as it originally did, to challenging power and

demanding expanded rights and access, self-advocacy when institutionalized often refers to knowledge of system navigation, including individuals having the knowledge or ability to choose from services that are on offer, having interpersonal skills that align with professionals, and having confidence within meetings (Aspis, 2002; Bruce & Aylward, 2021). Essentially, although the original self-advocacy movement included a more boundless challenging of structures and supports with the aim of equalizing power, self-advocacy as used by higher education institutions (including the University of Victoria) is firmly boundaried and restricts self-advocacy to a specific set of options at a specific time. For example, as of May 2022 the University of Victoria Centre for Accessible Learning website had a "Self-Advocacy" tab that read: "As a student with a disability, you are the only person who knows both your own situation and your courses. We need **your** participation in developing a plan for access. Learning to self-advocate is an important part of transitioning through university. If you encounter difficulties we need to hear from you in order to resolve any problems" (original emphasis included; University of Victoria, n.d.). Such a message reads like an assigning of responsibility to the person with a disability that they engage with existing systems properly under threat of inadequate support. Due to both UVic's use of the term self-advocacy in this way, and the survey items from Study 1 that inspired Study 2 ("Expectation of being your own advocate in health or mental health services," "Navigating health and mental health services without guidance"), we used self-advocacy in conversation with participants in the current study in alignment with this institutionalized definition of self-advocacy, as it is the experience and limitations of this definition of selfadvocacy we are interested in.

Test and colleagues (2005) created a conceptual framework to define the components of self-advocacy among students with disabilities. This framework includes four components (Test

et al., 2005). *Knowledge of self* includes knowing about one's disability and one's strengths, interests, and preferences, whereas *knowledge of rights pertains* to knowledge of rights as a citizen and an individual with a disability (Test et al., 2005). *Communication skills* refer to skills that support the effective communication of this knowledge of self and rights, including negotiation, persuasion, compromise, and assertiveness (Test et al., 2005). *Leadership skills* are less uniformly included in definitions of self-advocacy, as it is assumed that one can be an effective self-advocate at the individual level without having leadership skills; but leadership skills are necessary if self-advocacy is pursued at a higher systems level (Test et al., 2005).

Importantly, in existing literature self-advocacy is not assumed to be a natural skill that is acquired, but it is assumed to be one that requires explicit teaching and support to develop (Daly-Cano et al., 2015; Test et al., 2005; White et al., 2014). For successful self-advocacy, it is recommended that individuals have positive personal and professional support to regularly collaborate with students to determine how their self-advocacy efforts are proceeding and provide modifications or strategies for students (Daly-Cano et al., 2015). Explicit self-advocacy teaching is theorized to be most effective when it is started early (i.e., elementary school), is repeated, and offers supportive relationships for individuals with disabilities to practice and develop their self-advocacy skills (Daly-Cano et al., 2015; Test et al., 2005; White et al., 2014). Despite this noted importance of teaching, there is a lack of evidence of the efficacy of self-advocacy training, with interventions often examining short-term outcomes (e.g., improved knowledge and skills) without examining whether improved knowledge or skills in self-advocacy in fact lead to better outcomes in receiving support (Palmer, 2000; Roberts et al., 2016). Thus, although self-advocacy is well-defined and interventions are developed to support

self-advocacy, the actual practical outcomes of having greater self-advocacy skills is largely unknown.

Theorists have argued that the application of self-advocacy to university students with mental health challenges is inappropriate (Daly-Cano et al., 2015; Kartovicky, 2020; McEwan & Downie, 2013; Palmer, 2000). First, as it is typically described, self-advocacy is a lifelong skill which needs to be supported and developed among students with disabilities, ideally starting in elementary school. Yet most students with mental health challenges do not develop those challenges until much later in life. Although some mental health challenges and neurodevelopmental disorders may be diagnosed at an early age, many are not, and students may experience a first onset or diagnosis of mental health challenges during their time at university (Daly-Cano et al., 2015; Kartovicky, 2020; McEwan & Downie, 2013). Thus, such students are developing knowledge of both self and of rights much later than individuals with longer standing disability, often with less support, thus making it less likely that self-advocacy knowledge has been developed (McEwan & Downie, 2013). Further, Palmer (2000) notes that it may not always be in people's best interests to self-advocate for their disability rights, especially in university, as it could potentially negatively impact how they are treated by professors and future opportunities (e.g., to work with professors, to have positive references). Thus, it is already known that there are inherent limitations in the application of self-advocacy narratives to university students with mental health challenges.

In the current study, we sought to better understand how self-advocacy is experienced by students with mental health challenges at the University of Victoria. We were interested not only in how individuals describe these experiences, but also suggestions to improve student abilities to effectively navigate systems and access supports. Thus, the initial research aims of Study 2

were as follows: 1) to explore how students at the University of Victoria with mental health challenges discuss their experiences of self-advocacy during their time in university, 2) to collect knowledge on how students with mental health challenges navigate support services, and 3) to understand what types of solutions students propose to barriers related to self-advocacy.

#### Method

## Epistemology and Guiding Frameworks

In Study 2, I have chosen to take a social constructionist stance. Social constructionism posits that experience on its own holds a variety of potential meanings, and meaning is developed through interaction with a conscious, interpreting agent within a particular social and symbolic context (Crotty, 1998). This stance acknowledges that language is used to construct reality, and that it is not just direct experiences that should be considered, but also the impacts of constructing reality in a certain way (Gergen et al., 2015). This aligns with the theoretical frameworks that I outlined in Chapter 1, including psychocentrism and psy dominance, which acknowledge both the present dominant Canadian societal tendency to individualize suffering and struggle, as opposed to connecting these experiences to larger structural forces, and the impacts this has on individual understandings and societal conditions for individuals with mental health challenges (Costa et al., 2012; Holland, 2018; Rimke, 2016). Concretely, this means that the procedures and analysis of Study 2 are not solely focused on the content of participants' experiences, though this remains important, but they also focus on the meaning and impact is created by constructing experience in a particular way. I adopt this stance not only because of its alignment with key theoretical frameworks, but also because of its relation to a criticism of participatory research: that local knowledge can be prioritized at the expense of attending to the larger structures and forces that shape local knowledge, thus maintaining the status quo as

opposed to disrupting it (Strumińska-Kutra, 2016). At the same time, another criticism of participatory methods is that it can be focused on long-term, comprehensive social change when smaller, more urgent local change is also needed (Reason et al., 2011). Thus, I aim to additionally consider the urgency of the lived experience of participants in both my methods and analysis. Practically, this means balancing between a critical perspective of the way language is used by participants and how such language use relates to the types of challenges and solutions identified by participants, while also focusing on the specific content of what participants are sharing to ensure the concrete challenges and ideas for solutions they identify are presented.

# **Participants**

I recruited participants via e-mails to participants who completed Study 1 and expressed interest in workshop participation, and through new advertisements disseminated through social media. Inclusion criteria were having experienced impactful mental health challenges and being a current or former University of Victoria student.

Twenty-one participants with lived experience of mental health challenges participated in this study (see Table 25 for demographic information, and Table 26 for mental health information). Twenty participants attended hybrid (i.e., simultaneous in-person and Zoom) workshops to collaborate with the research team on further exploring experiences of self-advocacy, and to brainstorm how to address barriers related to self-advocacy. One participant who was not comfortable attending group workshops responded to all questions in an individual meeting with me. Twenty participants attended the first workshop (9 in-person, 11 on Zoom), and 15 attended the second workshop (7 in-person, 8 on Zoom). One participant who could attend the first, but not the second due to personal scheduling conflicts, workshop responded to questions individually. Other participants who attended the first, but not the second provided

reasons such as needing to prioritize academic and personal commitments. One participant did not identify a reason for not attending the second workshop. Participants were compensated at the hourly rate designated for research assistants (\$17.12/hour) to honour their role as collaborators.

 Table 25

 Demographic Information of Workshop Participants

Characteristic	n	%
Gender		
Men	1	5.3
Transgender, nonbinary, or questioning	4	21.1
Women	14	73.7
Sexual Orientation		
Bisexual	8	42.1
Gay or lesbian	1	5.3
Heterosexual/straight	7	36.8
Queer	1	5.3
Questioning	2	10.5
Ethnic Background*		
European origin	3	15.8
North American Indigenous origins	1	5.3
Other North American Origins	4	21.1
Religious ethnic group	1	5.3
Southeast Asian	1	5.3
White, not otherwise specified	9	47.4
Highest Education Level Achieved		
Grade 12	4	21.1
One year post-secondary	3	15.8
Two years post-secondary	2	10.5
Three years post-secondary	3	15.8
Four years post-secondary	2	10.5
Five years or more post-secondary	5	26.3
Faculty		
Education	2	10.5
Engineering	2	10.5

Fine Arts	2	10.5
Human & Social Development	1	5.3
Humanities	1	5.3
Science	3	15.8
Social Sciences	8	42.1
Racial Minority		
Yes	3	15.8
No	16	84.2
Financial Status		
Comfortable, with extra	3	15.8
Comfortable, but no extra	8	42.1
Have to cut back	4	21.1
Cannot make ends meet	4	21.1
First Generation Postsecondary Student		
Yes	6	31.6
No	13	68.4
Citizen of Canada		
Yes	19	100
No	0	0
Comorbid physical health concerns		
Yes	6	31.6
No	13	68.4

*Note*. The demographic questionnaire was completed by 19 out of 21 participants. Percentages represent the percentage out of the 19 participants who completed the questionnaire. \*Individuals were able to write as many ethnic backgrounds as were applicable to them, and thus the total ethnic backgrounds sums to greater than the total number of participants, and the percentages do not add up to 100%.

 Table 26

 Mental Health Diagnoses and Symptoms of Workshop Participants

Characteristic	n	%
Mental Health or Neurodevelopmental Diagnosis*		
Anxiety disorder	14	73.7
Depressive disorder	13	68.4
Attention deficit/hyperactivity disorder	2	10.5
Borderline personality disorder	3	15.8

Body dysmorphic disorder	1	5.3
Gender dysphoria	1	5.3
Post-traumatic stress disorder	2	10.5
Eating disorder	2	10.5
Obsessive-compulsive disorder	1	5.3
Bipolar disorder	2	10.5
Autism spectrum disorder	1	5.3
Learning disability	1	5.3
No diagnoses	2	10.5
Symptoms*		
Impulsivity, excessive energy or joy, aggression, anger,		
easily frustrated, thrill-seeking behavior, unhealthy	13	68.4
substance use		
Self-injury (e.g., cutting, burning, skin-picking, hair-pulling)	13	68.4
Excessive sadness, low motivation, loss of pleasure, low		
self-worth, self-blame, suicidal ideation, worry (e.g., specific fears or worries, social situations, overarching	19	100
worry), racing thoughts		
High levels of stress or challenges related to experience of		
trauma/life stress (e.g., flashbacks, hypersensitive to	12	63.2
surroundings, nightmares, detachment of reality,	12	03.2
"blacking out")		
Challenges with body image, extreme weight loss	15	78.9
strategies, binge eating, fear of gaining weight		, 515
Challenges with social communication, changes in		
routine, physical touch, attention, concentration or	16	84.2
learning, repetitive behaviors/movements (e.g., shaking,		
body rocking, head banging)		
False beliefs of what one is seeing or hearing,	4	21.1
disconnection from reality		
Uncomfortable physical sensations (e.g., headaches, nausea/vomiting, fatigue, sleep disturbances, fidgety,	17	89.4
racing heart, chest pain, dizzy, muscle tension)	1 /	09. <del>4</del>
racing near, enest pain, aizzy, masere tension)		

*Note.* The demographic questionnaire was completed by 19 out of 21 participants. Percentages represent the percentage out of the 19 participants who completed the questionnaire. \*Individuals were able to write as many diagnoses and select as many symptoms as were applicable to them, and thus the total diagnoses and symptoms sum to greater than the total number of participants, and the percentages do not add up to 100%.

Before the workshops, I met one-on-one with participants. Our research team felt that this meeting was essential to foster open sharing within the workshops by ensuring that participants

were familiar with me, and to ensure that we were attuned to participants' accessibility needs. During this meeting, I provided participants with information about the study and gave them the opportunity to ask any questions they may have. I also asked for their input on how the workshop could be most comfortable for them (e.g., accessibility needs, Zoom versus in-person participation). If participants identified that participation in a workshop may be inaccessible for them (e.g., length of workshop, anxiety entering new situations, group communication struggles), they were offered the option to answer the workshop questions in an individual interview or in written form. Workshop participants completed the same demographics questionnaire as used in Study 1 (see Appendix A).

Sample Size. Our sample size is in keeping with the data collection method (World Café), which prioritizes collecting data from enough participants that diverse perspectives will be represented (i.e., students from different marginalized groups, educational backgrounds), while keeping to a small enough size that participants will have time to meaningfully share their own experiences and connect with others (Brown & Isaacs, 2005). This sample size is also in keeping with the data analytic method, reflexive thematic analysis (see section "Data Analysis" for further details). In this method, the goal is not a complete and finished understanding, but rather a sample size that supports the method being used in conjunction with thematic analysis, the aims of the study, the richness of the data, and the experience level of the researcher (Braun & Clarke, 2021b). Due to multiple indicators suggesting a smaller sample size would be appropriate (e.g., rich data via participant narratives, relatively homogenous sample of individuals with lived experience of mental health challenges at the University of Victoria), I decided on a sample size that is on the lower end of the sample size that aligns with World Café, approximately twenty participants. Given the focused nature of the questions being asked of

participants, and the process of the workshop which allows for participants themselves to contribute to theme development (see the following section for further details), I believe this sample size was sufficient to support adequate data collection and analysis.

# Barriers to Self-Advocacy for Students with Mental Health Challenges: A World Café

I introduced our research team to the World Café methodology and other alternatives (e.g., focus groups, individual interviews), and we decided to use World Cafe, making several adaptations to ensure we were prioritizing accessibility and participant sense of safety. We conducted a two-part workshop with the same participants attending both parts, with the workshops held one week apart. Workshops were three hours per session, for a total of six hours. The workshops were audio recorded and transcribed, and data participants shared on a virtual "corkboard" (made using Padlet) as part of the workshop were collected for analysis. Participants also completed a debriefing survey within one to three weeks after the workshop. The first part of the workshop focused on exploring insights and narratives related to self-advocacy, and the second part was solution-focused and asked participants more explicitly for recommendations as well as their own knowledge to contribute to a resource to support students.

The World Café method is based on the idea that conversations that create change often happen informally, such as in coffee house conversations between friends (Brown & Isaacs, 2006). Though not initially intended for research, the World Café method has been used in multiple research projects, and in particular appears in conjunction with participatory methods (e.g., Löhr et al., 2020; Sheridan et al., 2010; Steier et al., 2017). World Café is unique in that both the results and the process of holding workshops can create change. This method embeds accessibility of sharing within its methods, offering participants multiple means to share ideas, including through self-reflection, small group conversations among table members, and written

forms (Brown & Isaacs, 2005; Estacio & Karic, 2016). Further, a major component of World Café is that it fosters network extension among participants, and fosters potential continuing relationships both among participants and with researchers to continue to think about and address complex issues (Löhr et al., 2020; Ropes, van Kleef, & Douven, 2020). This method has also been noted to provide a balance between gathering individual views, while also being able to gather data more quickly from a larger, more diverse group of participants (Löhr et al., 2020).

World Café is a flexible method with seven general principles to follow when designing:

1) setting the context, 2) creating hospitable space, 3) creating meaningful questions, 4)
encouraging everyone's contribution, 5) cross-pollinating diverse perspectives, 6) encouraging
participants to listen together for insights, and 7) sharing collective discoveries (Brown & Isaacs,
2005; Steier et al., 2017). The first step, setting the context both within the research team and at
the workshop itself, involves providing rationale for why the World Café is happening and what
the key elements are. Here, we provided the rationale for our Café to participants both through
individual meetings that occurred in advance of the workshop, through a brochure which
provided more information about workshop structure and the research team, and when the
workshop commenced (Brown & Isaacs, 2005).

We approached the second step, creating hospitable space, differently depending on whether participants attended on Zoom or in-person. The creation of hospitable space commenced before the workshop via asking participants for their input on accessibility needs, group guidelines, and participation preferences. The workshops were held in late January and early February of 2022, immediately following the University of Victoria re-opening after the first omicron wave of the COVID-19 pandemic. Thus, we balanced creating hospitable space with safety concerns of COVID-19 (e.g., minimizing multi-touch services, maintaining adequate

social distancing). In-person workshops were held at the University of Victoria campus. We booked multiple small classrooms, and in-person groups rotated between different classrooms. Greeters welcomed participants to the workshops, desks were re-arranged to create small circles for groups in each room, COVID safe snacks were provided during breaks, and various comfort materials were supplied (e.g., blankets, colouring books, fidgets) (Brown & Isaacs, 2005). For those on Zoom, welcoming images were provided using the "Share Screen" function, and participants were invited to bring their own food and beverages and to participate in a way that facilitated their comfort.

Third, we created meaningful questions to support in-depth sharing. Our workshop contained several narrative questions (i.e., asking participants to tell stories of their experiences). The key features of questions in World Café are that they are open-ended, encourage sharing of diverse perspectives and brainstorming, allow participants multiple mechanisms to share (e.g., through discussion or written forms), and allow time for reflection of participants on deeper meanings and themes. We created questions aligned with these principles (see Appendix D).

Three points of design of the World Café, encouraging everyone's contribution, cross-pollinating diverse perspectives, and encouraging participants to listen together for insights, are interrelated and are met by ensuring certain process elements of the Café have been considered (Brown & Isaacs, 2005). In line with guidance from the developers of World Café, we encouraged everyone's contribution through sharing of group guidelines prior to the workshop and at the start of each session, having facilitators within small group discussion to moderate discussion, and having multiple accessible means of sharing (Brown & Isaacs, 2005). We achieved cross-pollination of diverse perspectives through the workshop structure which encourages both self-reflection to ground participants in their own perspectives and participation

in different groups of students (Brown & Isaacs, 2005). Participants were broken up into five groups in Part 1 of the workshop (three in-person, two on Zoom), and four groups in Part 2 (two in-person, two on Zoom). Groups size varied between three and six participants per group. Although it is typical for groups to shift each question in World Café, our research team decided during Part 1 of the workshop to maintain the same groups throughout. This was due to a high level of emotion being expressed in some groups related to personal narratives, and a vocalized desire of participants within the workshop to stay in the same groups to improve their comfort and openness. Because Part 2 of the workshop involved less personal sharing, groups shifted each question. Because participants were split between Zoom and in-person, with no easy way to have hybrid groups, cross-pollination of perspectives was somewhat limited, in that in-person and Zoom participants were separate throughout the workshop. Finally, encouraging participants to listen together for insights was fostered in a variety of ways. First, our narrative question design explicitly asked individuals to share their insights as they listened to each other's stories. Additionally, the embedding of self-reflection time and opportunity to post summative statements on a virtual corkboard as the workshop progressed allowed individuals to more deeply reflect on what was being discussed in the workshop.

Current and former students with lived experience of mental health challenges facilitated the workshops. Either one or two facilitators were within each group, according to facilitator preferences and number of attendees. Facilitators helped the process of sharing, reminded group members of group guidelines, and noted down observations or themes to be later used in data analysis (Brown & Isaacs, 2005). I trained facilitators prior to the workshops.

The final step indicated within the World Café method is sharing collective discoveries (Brown & Isaacs, 2005). This was done within the workshop via the various visual means of

sharing, which, in the case of our design, involved participants sharing their thoughts on a virtual "corkboard" created with Padlet, which was viewable to all participants. The use of a virtual corkboard allowed collective discoveries to be shared between in-person and Zoom participants. Sharing collective discoveries also continues after the workshop ends by prioritizing accessibility in sharing of findings back with participants and relevant community members, which I will discuss further in Chapter 5.

## Data Analysis Rationale

As World Café was not originally developed for research purposes, there is no type of data analysis that is specifically recommended to use in conjunction with this method, and indeed previous research using World Café has been analyzed using a variety of methods, such as various forms of thematic analysis (e.g., Estacio & Karic, 2016; Khong et al., 2017; McDermott et al., 2020) and qualitative content analysis (e.g., Löhr et al., 2020), and with a variety of content focuses (e.g., analysis of only written data versus analysis of recording). Thus, I chose to analyze data using reflexive thematic analysis (Braun & Clarke, 2019, 2021a, 2021c) while incorporating unique considerations due to the nature of group data (Kidd & Parshall, 2000; Morgan, 2010).

Reflexive thematic analysis calls on the researcher to undergo their own process of reflection on their values, personal positioning, assumptions, relationship to participants, and disciplinary location, and how the intersections of these relate to the data analysis process and outcomes (Braun & Clarke, 2021b). Thus, this method is a natural fit to the participatory stance taken within this dissertation, which also emphasizes that the researcher must reflect on and incorporate the way their professional, political, and social selves are linked to the research process and findings (Lake & Wendland, 2018). Thus, a central part of the data analysis process

is keeping my own journal of reflections on how the analysis is influenced by my own experience and philosophical underpinnings, and how this in turn influences my decision-making processes. This type of analysis eschews traditional notions of reliability, and in general the idea that the goal of research is to find objective truth, which may be found in other forms of qualitative data analysis via concepts such as interrater reliability (Braun & Clarke, 2021a). Reflexive thematic analysis instead suggests that qualitative analysis is inextricably linked to the researcher conducting the analysis, and that quality is attained not by attempting to adhere to quantitative methods standards, but rather by striving for a "stronger" (e.g., in-depth, insightful, nuanced) versus "weaker" (e.g., superficial, shallow) analysis (Braun & Clarke, 2021b).

An additional strength of thematic analysis is it allows the ability to be flexibly used to analyze both individual and group data, both of which existed within this project. Although several concrete considerations in coding between group and individual data will be discussed later, theoretically, thematic analysis is more flexible within type of data to analyze, as the focus of analysis is on establishing themes across individuals and groups, as opposed to other forms of qualitative data analysis (e.g., interpretive phenomenological analysis), which have more specific requirements for data, such as that individual narratives be analyzed separately before being combined with others (Braun & Clarke, 2021a).

### Data Analysis Procedure

I will outline the six steps associated with reflexive thematic analysis, specifying what was done in this data analysis and including unique considerations for group data. The first step is familiarization with the data, which involved the process of transcription and reading of the data before beginning coding (Braun & Clarke, 2006). The second step is to begin coding the data. Aligned with guidance both about reflexive thematic analysis (Braun & Clarke, 2019) and

analysis of qualitative group data (Kidd & Parshall, 2000), I coded the data independently. Given the emphasis on reflexivity, the aim of reflexive thematic analysis is not to achieve consensus with multiple coders, but for the coding to be consistent across the data, and for the influence of the coder's experiences and theoretical perspectives to be explicated (Braun & Clarke, 2019, 2021c). That being said, due to the participatory nature of this project and the role that multiple facilitators played in data collection, it was important to remain connected to the perspectives of the research team (Kidd & Parshall, 2000). Thus, we held ongoing meetings with the research team to discuss both my coding and reflections, and for the research team to offer feedback and their own perspectives on the data analysis as it unfolds. For group data, it is recommended that coding occur both at a more fine-grained level (e.g., shorter statements by one individual) as well as within larger units (e.g., stories, back-and-forth discussion) so that both individual perspectives and perspectives developed through discussion, agreement, or disagreement can be captured within the analysis (Kidd & Parshall, 2000).

The following three steps of thematic analysis refer to theme development: 1) generating initial themes from codes and coded data, 2) reviewing and developing themes, and 3) defining, naming, and refining themes (Braun & Clarke, 2006). As coding progressed, I continually reviewed and developed themes, as it is assumed in reflexive thematic analysis that codes and themes should change with greater exposure to the data and greater insight gained through interaction with the data over time (Braun & Clarke, 2021c, 2021b). Further, in alignment with guidance both from reflexive thematic analysis and guidelines for coding qualitative group data, frequency was not seen as the sole marker of importance when developing themes (Braun & Clarke, 2021b; Kidd & Parshall, 2000). Thus, whether something was established as a theme was dependent on the context of discussion was considered when establishing importance. By the end

of the reflexive thematic analysis, I aimed to develop rich, complex, and multifaceted themes united by a shared idea or concept as opposed to a more superficial content relation (Braun & Clarke, 2021b). Importantly, though I have in some sense "completed" the reflexive thematic analysis presented below, even the themes presented within a dissertation are not considered "final." The stance of reflexive thematic analysis is that ending themes are provisional, and could be further refined through ongoing engagement (Braun & Clarke, 2021b).

The final step of thematic analysis is writing up the report (Braun & Clarke, 2006). Several qualities of a report created from thematic analysis differ from what would be reported in quantitative analysis. First, it is recommended that what would typically be written as a "Results" and "Discussion" be integrated into a "Findings" section (Braun & Clarke, 2021b). This labelling aligns with the stance that the analysis is the result of a particular researcher in a particular context in a particular time, and is not final as may be implied by a "Results" section (Braun & Clarke, 2021b). The incorporation of extant literature and interpretation of the findings within the Findings section aligns with the notion that the data and accompanying analysis is influenced by my own prior and evolving scholarly knowledge, and contextually situated within the environment in which other research has arisen, and thus the analysis is inextricable from existing knowledge.

### Findings

# Theme 1: The Structural Context of Self-Advocacy: No Space for Mental Health Challenges

The structural context in which students were being asked to self-advocate was central to understanding the experience of self-advocacy. In this regard, I heard students describe a system that felt hopeless to meet their needs. Some participants were unaware that services existed to support students with mental health challenges, and others who had sought services found the

system was profoundly limited. Despite these limitations, students still told stories of battling for access to limited resources within a system that felt unfair and out of touch with the reality of mental illness. This structural context resulted in a sense of apathy towards self-advocacy. In this case, then, the barriers related to self-advocacy were not only that it was challenging or burdensome on students who are already struggling, but also that they were being asked to self-advocate in a system that was designed to have no space for individuals with mental health challenges. As one participant simply stated, "We just have a culture that doesn't make room for... any kind of disability."

Invisible Support. Participants shared a lack of awareness that potential supports existed to support students with mental health challenges, and that these services were accessible to them. Typically, individuals had some knowledge of clinical mental health support (e.g., GPs, psychiatrists, counsellors) on campus, but did not know about other services (e.g., CAL, Peer Support Centre). As one participant described:

One of the problems I've had is just even knowing what the university offers. I had no idea about CAL or... the sexual violence place... none of them, not a clue... and even the Wellness Center. Figuring it out on your own is tough.<sup>1</sup>

This lack of awareness was particularly true of the Centre for Accessible Learning (CAL), as nearly every group discussed either not knowing about CAL and/or not knowing that mental health concerns could qualify one for support from CAL, as one participant stated:

[I] actually didn't know until just today that you can use your mental health as something to get accommodations. If I had known that I probably would have tried a little bit harder to get that... my mental health issues do interfere.

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<sup>&</sup>lt;sup>1</sup> Filler words were omitted throughout participant quotes to improve readability.

The workshop environment further highlighted for participants a lack of knowledge, as participants often responded to hearing others' experiences with surprise at not having heard of particular resources other individuals were sharing. For example, in one case a participant was discussing their ideal service, and was informed by another participant that such a service already existed:

Participant 1: I was thinking it would be cool if we could be volunteers to help other students navigate the university mental health system or advocate for them. If we want to, people who have had those experiences, who know the system well, and know the ins and outs could be... volunteers.

Participant 2: [Types in Zoom chat about Peer Support Centre offering this service]

Participant 1: Oh, is that a thing? The Peer Support Center? See, this is what I mean. The university is so ridiculous, I don't even know half the things that exists, and I've been here for six years.

Thus, one of the ways in which the concept of having no space for mental health was discussed was the invisibility of supports and services.

A number of reports have noted students with mental health challenges lack knowledge of services overall (Claiborne et al., 2011; Fossey et al., 2017; Giamos et al., 2017; Hartrey et al., 2017; Lindsay et al., 2018; Marsh & Wilcoxon, 2015), and lack knowledge that mental health challenges may qualify them for disability-related support (Claiborne et al., 2011; Giamos et al., 2017; McEwan & Downie, 2013). This is highly concerning given that several of the core tenets of self-advocacy relate to knowledge, both of self and of rights (Test et al., 2005). If individuals are not being given the information necessary to understand their rights and the systems in place to support them, then such individuals are not being given basic resources required for successful

self-advocacy. This relates to structural stigma, as it suggests normative institutional practice that excludes students from accessing services by way of maintaining services as largely invisible. Although the self-advocacy proponent may say that the information is there and students need to put in the effort to seek it out, this line of thinking falls apart when one considers how such a lack of knowledge impacts individuals in practice. If one has no knowledge of any space that exists to support them, why would they even think to look? What words would they use to search if they don't know that a service exists? What if they've never heard terms like "disability services" or "peer support"? Thus, it is perhaps unsurprising that one of the main barriers to accessing services is having no knowledge that such services exist or, if they do, not knowing whether one qualifies for such support (Chambers et al., 2013; Fossey et al., 2017; Giamos et al., 2017; Hartrey et al., 2017; Lindsay et al., 2018; McEwan & Downie, 2013; Megivern et al., 2003; O'Shea & Kaplan, 2018).

Even when participants did have knowledge that the service existed, participants reported other layers of knowledge that were missing that discouraged them from accessing services, such as not knowing where to find the service, not knowing if the service was appropriate to meet their particular needs, and not knowing whether there was a cost associated with the service. For example, one participant discussed:

I was already not at a great point when I came in the summer beforehand, and so I was looking for counselling services. And I obviously started with UVic Counselling, which was difficult, because I didn't know where on campus it was, I didn't know what to do...

And it was really frustrating, because I didn't have any support and right from the get go. Similarly, another participant expressed frustration at knowing about the existence of multiple services, but not understanding the role of each:

I think the biggest barrier for me is just not knowing what resources there are, and what they all do. I have this issue of, do I go to CAL? Do I go to counseling? Is it not something that I should really bring to either of those?

Within the workshop, participants also discussed the lack of transparency about the cost associated with different services, and their confusion about whether services were free or not:

Participant 1: I think the campus services are covered. I don't know if you're trying to look at other services.

Participant 2: I just meant campus. Yeah. Okay, well, that's good.

Participant 1: Not super sure how it works, because I opted out of that health plan and it's still covered for me somehow.

Participant 2: Okay, cool.

Facilitator: Well, that kind of brings up another point, doesn't it? No one knew if they were going to have to pay for it or not.

Participant 1: I think there should be more information about the health coverage that you're paying for that you either opt in or out of when you pay your tuition that if that covers counselling and... what of the campus services are covered. And what, if you want to look elsewhere, is not covered because I don't know about any of you, but I don't even know where I would find that information if I wanted to.

This lack of clarity around finances is worth emphasizing, given that the cost of services is a noted barrier to accessing services among university students (Marsh & Wilcoxon, 2015). It is also notable when paired with the finding from Study 1 of this dissertation that financially stressed students experienced greater impact of various barriers, including barriers related to service navigation and practical support knowledge. This lack of clarity around financial

ramifications of seeking services thus provides a potential mechanism to explain why students who are financially stressed are most negatively impacted by assumptions of self-advocacy. Specifically, when a lack of clear information about financial costs is available, students may assume (correctly or incorrectly) such services have a cost associated and not seek them out in the first place. This provides important nuances to issues of access. When students cannot access clear information about services, they may be intimidated, confused, or frustrated when attempting to access services. They may also have concerns about potential consequences of seeking services (e.g., financial, unnecessary disclosure), and thus not seek out support due to lack of accessible information.

Inadequate Support. More commonly than participants expressing no knowledge of services or supports, participants expressed that they had sought support, but found that services were inadequate in a variety of ways. Every group discussed limitations to existing services, including that they were challenging to navigate, inaccessible, over-burdened, delayed, or not applicable to their particular concerns. All of these limitations have been found within the mental health services available at several other universities (Chang et al., 2020; Hartrey et al., 2017; Markoulakis & Kirsh, 2013). Participants also described a key limitation of existing services being that services designed to meet the needs of students with mental health challenges appeared to be designed without the struggles and limitations associated with mental health challenges in mind.

When reading the participant descriptions of existing services, I was reminded of a quote from Luhrmann (2007), describing the housing services for women diagnosed with schizophrenia as a "genuinely confusing and inherently disorganized array of services" (p. 158).

These adjectives apply to the service system at the University of Victoria as well, as one participant in our study described:

When you already have a mental illness or a mental health disorder, you're exhausted and potentially debilitated, and it's really hard to navigate those things. And even if you try to, like you all mentioned, you get put on this goose chase to find the thing you're looking for or access the thing you need.

Several participants discussed a dizzying cycle of being referred to different services, of being required to have gone through certain services in order to gain access to others, or of simply being told a certain service was not available to them with no guidance for alternative options. Central to this cycle were also challenges finding a knowledgeable person or resource to help them to navigate the system. De Bie (2019) writes of the negative impact of these referral loops, most notably arguing that they can result in very few (if any) staff and faculty feeling responsible to work with students to support them. Here, service providers can easily disregard requests for supports as inappropriate or outside of their specific purview, instead "referring out," thus ridding oneself of felt responsibility to support access. Bruce and Aylward (2021) described a similar phenomenon among students with disabilities at another Canadian university, where selfadvocacy required not only, and not even most importantly, a knowledge of rights, but of process: of who to go to and when, submission deadlines that must be met to gain access, and of the order in which tasks are to be completed. Thus, it appears that self-advocacy as it exists in the university today not only requires that students know what rights they are entitled to, but also the complex processes they must undergo if they wish to attain those rights.

Further, simply knowing about and reaching out to a service did not guarantee support.

One participant stated, "It almost feels impossible to even get an appointment. Right? So how do

I even start when I can't even get into the spot to get help?" Another participant described an experience with CAL where they felt intimidated and unwelcomed by the service, and couldn't access the information they desired in a way that felt respectful:

When I finally did actually reach out to the CAL, they wouldn't talk to me at all... I wanted to talk to someone to humanize the experience a bit. And I wanted to actually speak to somebody who worked there saying what kind of things they can offer, and they just wouldn't let me pass the front door. I tried emailing, calling. I even walked in one time... Every time they just said, 'Nope, we can't talk to you unless... we have your personal medical records.' And that was something that was hard.

This made participants skeptical of narratives that implied that "just reaching out for help" was sufficient, as several shared experiences of reaching out and being turned away or needing to first complete complex processes to have access to basic support.

When participants did successfully reach out and get connected with services, participants reported being negatively impacted by long wait times and delayed access to services, a common issue in university mental health services (Giamos et al., 2017) and one of the most impactful barriers identified in Study 1 of this dissertation. This relates to a larger societal context of under-supporting, through lack of funding and lack of coverage, access to existing mental health services, representing overarching structural stigma in healthcare (Livingston, 2020). This seemed to be particularly emotional for participants, as several either described being tearful at the time of being informed of wait times or became tearful within the workshop describing the disappointment associated with being told to wait:

When you're really struggling, it's hard enough to get yourself to go to book an appointment. And then to be told you have to wait five weeks... it's just so discouraging.

I went one time, and then cried afterwards, because it was going to be such a long wait. I got all the way home before realizing mascara was down my face, and I've been walking around.

Chang and colleagues (2020) have noted the emotional impact of university mental health service failures, and specifically the potential for individuals with mental health challenges to view limitations in services as disregarding or invalidating the distress they are in. Participants in our workshop echoed this sentiment. Further, in our workshops it seemed to me that delays in access to services contributed to hopelessness and a sense of abandonment among students, reinforcing the idea that, when struggling, help was not and would not be available.

The time delays associated with accessing services led participants to feel that support was not available in emergency or crisis situations. Several participants expressed opinions that services were irrelevant, as personal crises or sudden declines in mental health were common in their lives. One participant described:

This was maybe two months ago where I had a family emergency, and I put everything on hold for school... it was not my immediate priority. And when things kind of died down one or two days later, I was just, like, okay, I just have to stay up all night and finish everything, because trying to find accommodations is just not going to... it's not going to work and it's adding to the stress.

Thus, it was clear that for this participant and others, tacit knowledge of the bureaucracy and time delays in access to support led to perceptions that seeking support in crisis situations would just be another stressor on an already overwhelming to-do list. Further, given the brief nature of semesters, several expressed that several week to months delays felt too late to receive help, as

by that time mental health challenges will have already negatively impacted their academics in a way that felt beyond repair.

Somewhat paradoxically, several groups also discussed how no support for ongoing mental health challenges was available. This created a seemingly contradictory description where services were both not helpful for emergency support because they were so delayed and difficult to access, but were also not helpful for ongoing support because services were taxed by trying to provide short-term, crisis support to students, even though this support was not timely. Many participants in our study described long-standing and deep-seated mental health challenges, and thus only being able to access support for a short period or in crisis was seen as providing "a band-aid over a bullet hole." Thus, it was felt by many that existing mental health supports, though perhaps providing temporary relief, would not be able to offer effective support to heal from mental health challenges:

I think some of that sort of really short term stuff, when there's longer ongoing problems, erodes trust or the ability for people to truly open up to process some of the harder things going on. So none of that deeper stuff ever really gets addressed. Because you're just conscious of, well, I can't trust this person too much, because it's going to end at some point, so [I] don't want to get too deep and then just be left alone.

Several participants reported that they sought private mental health services to access more consistent and timely support. However, most participants did not have the financial security to pursue this option.

Nearly every group discussed how service limitations were related to higher-level structural barriers, especially over-burdened services. For example, one participant stated:

I understand it's not the counsellors' fault. It's just there's not enough of them for the amount of people who are trying to get help. But it's kind of like, well, there should be more. You've got this many students... interested.

The over-burdened nature of mental health services is commonplace in university, and is often attributed to universities wanting to diversify their campuses without concomitant investments in the supports necessary for the success of a diverse student body (Giamos et al., 2017; Mowbray et al., 2006; Ng & Padjen, 2019). This over-burdened nature of services points to the inherent limitation of cultural views that necessitate professional support for mental health challenges, often to the detriment of broader community support. As Sarason (1974) states:

As long as mental health problems are defined in ways so as to require the service of professionals there is no solution. When defined in this way the discrepancy between the number of professionals and those deemed to need their service is scandalously large. (p. 189)

Highly limited support services within universities have been noted by other researchers (e.g., Chang et al., 2020; Hughes et al., 2016), and by a University of Victoria evaluation of disability-related services between 1994 and 2002 (Hibbs & Pothier, 2006). It is interesting, then, to reflect on what it means to require self-advocacy of students within such a highly strained and ineffective system. Bruce and Aylward (2021) propose that part of the corruption of self-advocacy narratives is that, although historically self-advocacy was meant to challenge systems of power to create justice for disabled people, self-advocacy as it is currently practiced within universities constrains the options of students with mental health challenges. Essentially, what is meant by "self-advocacy" in university is being able to navigate and select supports from a limited menu of options, a menu which may or may not contain services that actually support the

individual (Bruce & Aylward, 2021). Such an approach limits potential for institutional change, and instead legitimizes what is currently provided by institutions (Aspis, 2002). Although disability or mental health services may be implemented with the intention of being helpful, the system that was described by participants seems to have instead "the wasting of time and the depletion of energies built into its bolts" (Dolmage, 2017, p. 77).

Exclusionary Supports: Assumptions of Ability in Self-Advocacy. Support services also appeared to be designed without students with mental health challenges in mind. This lack of inclusion of individuals with mental health challenges in developing and informing the services that impact them is a form of structural stigma rooted in beliefs that individuals with mental health challenges cannot know their needs with the same level of sophistication as professionals (Livingston, 2013). Specifically, participants described several disheartening experiences where it seemed the service they were trying to access for support operated in such a way that either highlighted or did not acknowledge their limitations. Whereas the functional limitations associated with mental health challenges are known and noted among students with mental health challenges, including poor concentration, attention, and motivation, tiredness, exhaustion, low mood, negative self-perceptions, and feelings of guilt and failure (Hartrey et al., 2017), support services seemed to ignore this reality. Instead, support services seemed to assume that students were able to navigate the many complex tasks involved in acquiring support, regardless of limitations associated with disability. Participants described this in several ways. For example, they explained how the website for CAL is filled with large bodies of small text, making it challenging for someone with dyslexia to read. The website also provides long lists of services that students must independently navigate, a task that is difficult for someone who is struggling with ADHD. At a more fundamental level, the process of self-advocacy itself was

described as misunderstanding the needs and limitations of individuals struggling with their mental health. As one participant summarized:

I would like the school to recognize how counterintuitive it is to have people with mental health issues advocating for themselves when it's, I think, a fairly well-known idea that people with mental health concerns generally struggle to practice simple self-care, let alone putting in all that effort. So, I just think that that's something that the school should consider with maybe a more neurodiverse mindset.

Participants described specific lived experience with mental health challenges that hindered their ability to self-advocate. This included, for example, having no energy to reach out when mental health was poor:

In my opinion, if I'm feeling like anxious or depressed, I really don't have the energy to [access support services]... I'm not even really worrying about school. I don't know. I'm just trying to keep myself above water.

Individuals also felt that rejection or delay in services could reinforce feelings of loneliness and unworthiness that were described as typical of individuals struggling with their mental health: "I know when you're struggling you feel like it's just you and it's like you're doing everything wrong... you're failing to meet these criterias." Participants also described challenges in explaining their mental health. These challenges were related both to mental health symptoms and to the intersection of mental health and age, such that younger students may not have the knowledge or vocabulary to properly convey to a professional what they were struggling with and what help they were seeking. One participant described their symptoms of mental health challenges as impacting their ability to self-advocate: "With my social anxiety, it's really hard to talk to them and tell them, 'this is what I need.'" Thus, the construction of services for students

with mental health challenges does not appear to consider how symptoms and signs of mental health may impact individuals' abilities to access services. This is not new information, as this lack of consideration was previously noted in a review of the University of Victoria's accommodation systems in the 1990s to early 2000s (Hibbs & Pothier, 2006). This issue may also help to explain why participants in Study 1 of this dissertation who reported more limited mental health functioning also reported a greater impact of barriers across nearly every domain. A similar phenomenon was noted in a study of self-advocacy at another Canadian university, which described a process whereby students had to earn their support by demonstrating the very abilities (e.g., time management, clear communication) for which they were seeking support (Bruce & Aylward, 2021). Bruce and Aywlard summarize this process well, writing "There is no small irony... in a system that recognizes and agrees to accommodate certain disabilities and simultaneously seems to require their disappearance" (2021, p. 18).

Dehumanizing Supports: Proving Suffering as a Way In. Students who sought certain supports, specifically through CAL, described a process of having to "earn" their way in via acquiring a diagnosis. In this process, too, participants described encountering a lack of space, this time because the diagnostic process and outcomes were challenging to access and, in some cases, did not align with their lived experience. Barriers within the diagnostic process have been discussed extensively in the literature. For example, researchers have argued that the process of seeking diagnosis requires individuals to prove they are disabled "enough" to be deserving of rights (Bruce & Aylward, 2021; Kruse & Oswal, 2018), that diagnosis provides only "conditional and temporary" access (Dolmage, 2017), and that the nature of diagnosis is time-consuming and expensive, thus risking making accommodations inaccessible to students with legitimate need (Chambers et al., 2013; Giamos et al., 2017; Hutcheon & Wolbring, 2012).

Further, this system excludes students who may have a disability that impacts their learning but is not recognized by the medical community (Hutcheon & Wolbring, 2012). In practice, diagnostic requirements can make support systems appear as though they begin by assuming attempted fraud by students and require proof to be convinced otherwise, which has consequences both for the accessibility of these services and the potential for maltreatment within these services (Hibbs & Pothier, 2006). In our workshop, participants described a range of barriers and challenges associated with diagnosis, including a lack of access to professionals who can diagnose, inequitable access to diagnosis, a contradiction between diagnosis and lived experience, negative personal impacts of diagnosis, and stigma associated with diagnoses. Participants felt these barriers were largely not acknowledged or accounted for in the administration of services.

Nearly all groups discussed that acquiring diagnosis is challenging, as participants reported a lack of access to knowledgeable professionals able to provide diagnosis:

Even with CAL, they... need confirmation that you've been diagnosed with something and not just be in the process of trying to seek out help for something. That also eliminates a lot of people because accessibility to those kinds of services are awful. And even just getting into an office to get diagnosed is hard.

Several participants also shared stories of going through multiple professionals who did not understand the criteria for certain diagnoses (e.g., ADHD), before finding a professional who was even knowledgeable enough to diagnose. This issue has been indicated in the larger literature, with a discussion of learning disorder diagnosis demonstrating that there is massive variation in how clinicians diagnose learning disorders, ranging from clinicians selecting different definitions or criteria for diagnosis, to the majority of clinicians not using any criteria

(Harrison & Holmes, 2012). Thus, the participants in our workshop were correctly identifying that whether or not one has a diagnosis is a function not only of the symptoms that you demonstrate, but also of whether you are able to see a professional and, when you do, which specific professional you happen to see.

Participants also highlighted that access to diagnosis is inequitable. Specifically, participants felt that diagnosis privileges those with the financial resources to pay for diagnostic services, and those from dominant Western cultures who are more likely to understand struggles with mental health in familiar diagnostic terms. Participants also felt that certain diagnoses (e.g., eating disorders, ADHD) had gender biases. For example, they described how it was harder to get a diagnosis of ADHD as a woman than as a man because the criteria are more structured to be reflective of ADHD in men. Finally, participants also discussed that diagnosis was inequitably accessible based on age, such that younger participants were less likely to have had the time, resources, and longer-term lived experience of mental health challenges necessary to acquire a formal diagnosis, relative to older participants. As one participant stated:

If you're fresh out of high school, and you're from a home that doesn't recognize mental illness or anything like that, and then you're coming to an area that does, the odds of you having a diagnosis are like nothing.

Hibbs and Pothier (2006) made a similar observation, stating that the idealized path of experiencing challenges, receiving diagnosis, presenting diagnosis, and receiving help is unrealistic. In reality, the path to mental healthcare is non-linear, complex, time-consuming, and inequitable, and in the end may be too costly and overwhelming to see through to fruition (Hibbs & Pothier, 2006).

Participants also expressed frustration that a diagnosis was required even when receiving a diagnosis or being denied a diagnosis may not agree with their lived experience. This points to another inherent limitation of diagnosis: that it requires individuals to, at least to a certain degree, adhere to institutionalized biomedical understandings of disability to access support (Hutcheon & Wolbring, 2012). For example, some participants felt that their particular mental health challenges did not always fit the "small box" required for diagnosis, but they accepted diagnoses that were not a good fit to their experience because they needed the level of support that only a diagnosis could provide. Participants also discussed how the narrowness of diagnostic criteria meant that some individuals who require the same level of support as individuals with diagnoses could be excluded on a technicality:

There's also bias inherent in certain diagnoses, where somebody may not qualify for a diagnosis by missing one tiny thing, but they still have that issue. It's just... it doesn't quite qualify in this narrowly defined way. So I think removing some of that barrier, like I'm thinking in particular, eating disorder diagnoses, and somebody might not qualify because they don't use a behavior this arbitrary number of times, or their weight isn't a certain expectation of what that should look like. That can really limit people in accessing support that's still very needed.

Further, participants were frustrated that diagnostic requirements did not seem aligned with professional knowledge on the nature of certain disorders. For example, several participants who had been diagnosed with learning disorders or ADHD as children were frustrated that they had to regularly have this diagnosis updated, as they identified both from their own experience and from professional knowledge about neurodevelopmental disorders that these diagnoses are

not something that is "cured," but something that is with them throughout life. As one participant described:

I just felt very, I guess, misunderstood just because dyslexia doesn't go away with age. So it's not something that just magically disappears when you're 18 or something. So I was kind of like, if I had it then, I have it now, I still have difficulty reading. I have difficulty processing information... I was just kind of frustrated. It is putting yourself in a vulnerable spot getting to be assessed... I felt like the people didn't understand what it was like to have a learning disability, and it was just ostracizing. I just felt like I wasn't very accepted or like I had to jump through another hoop to get something that I know that I'm qualified to get.

Participants also discussed a range of negative personal factors that impacted ability to seek out diagnosis, including not wanting to acknowledge their struggle, feeling like perhaps they were imagining their own struggle and did not deserve a diagnosis because it would just be an "excuse" for struggles that were due to internal factors such as lack of effort or lack of intelligence, and distress related to facing skepticism about the reality of their struggle. All of these impacts took place within the process of having to seek out assessment and potentially be denied diagnosis as this was seen to imply that participants' struggles were not "real." As one participant stated, "For me, I found it really hard to trust my capacity, because it just felt like everyone else can do the thing. Maybe I'm just not trying hard enough. And it's just, yeah, brutal." Another shared:

I was left feeling like I had to validate how awful my experience was when I wasn't even really equipped to understand what my situation was. I just knew that I wasn't well. And I think when you feel like you're having to prove how messed up you are, it leaves you

feeling so stripped... like you're almost an imposter. There's some insinuation that you're blowing things out of proportion or you're making things up because, oh, it's supposed to be hard.

These comments center the felt experience of participating in a system that is "based on a presumption of fraud" (Hibbs & Pothier, 2006, p. 211). Such a system seems to foster internalized stigma that can be developed or exacerbated within the process of diagnosis, as individuals are repetitively exposed to discriminatory beliefs as they seek support, and denial of support may be accompanied by insinuations that their struggles are due to personal failings such as lack of effort. Such insinuations may be internalized, resulting in individuals doubting their own perceptions of themselves, and instead internalizing ideas that they are "making excuses" or somehow being dishonest, to themselves and to others, about the nature of their experience.

Regardless of the outcome of diagnosis, the process can leave individuals feeling as though they do not belong in university because they are not able to function and adapt to university culture in the same way as others, and concerned that they are subconsciously "cheating" or "exaggerating" their experience in order to gain special privileges, as opposed to advocating to access rightful supports (Frederick et al., 2017).

Participants also described needing to balance competing interests when pursuing diagnosis. Specifically, participants described requiring diagnosis to have access to services and for others to treat their struggles as "real," but also that sometimes obtaining a diagnosis resulted in discrimination and beliefs of limited capacity. Essentially, participants were required to "earn" a diagnosis to access support, but by virtue of having a diagnosis, they may be shut out or discriminated against because they are seen as less capable than other students:

One of the things is that you need the diagnosis to access the support. But then I think also like [name]... was saying, sometimes then when you are trying to be open about that and share that you are having this experience, people just automatically assume that you aren't capable of doing something. So, it's like you can't win.

Both sides of this coin, needing to prove one's struggle to avoid beliefs that one is "faking" or "exaggerating" (O'Shea & Kaplan, 2018; Reid & Poole, 2013; Stein, 2013), but then facing prejudicial beliefs about capacity once the struggle is proven (Kruse & Oswal, 2018), have been noted as pervasive and impactful, and leave students in a precarious position where one can be stigmatized and denied access regardless of the steps they take.

The Practical and Psychological Impacts of a System with No Space. I have attempted to portray the construction of university systems the way it was portrayed by participants: as invisible, inadequate, exclusionary, and dehumanizing. It is worth noting that even among participants who described different or positive experiences with university services, there was still a sense that adequate support was rarely received. As one participant stated:

I haven't had many problems getting signed up with CAL and getting my accommodations, but the problems are that my professors just do not listen to them. I always send the [accommodation] letters, but I've had many times where they just didn't allow me to have the extension. One day, I was even in the hospital, and I still couldn't have an extension.

This aligns with previous findings that receiving support, including legally required accommodations, often ends up relying on willingness of individual faculty, with no larger structure ensuring support is rendered (Bruce & Aylward, 2021; Daly-cano et al., 2015; Fossey et al., 2017; Kartovicky, 2020; Markoulakis & Kirsh, 2013; Mullins & Preyde, 2013). Bruce and

Aylward (2021) sum this up by stating that disability rights are "theoretically protected yet realistically elusive" (p. 19). At the end of the first day of the workshop, several participants posted on our virtual corkboard their surprise and disappointment that negative experiences appeared to be so much more common than positive, as one participant wrote, "Feeling very angry and frustrated at the system and wondering why it's not better, and how it's so unfair so many people have to struggle so much."

It is worth reflecting on what impact these systemic limitations have on the idea of self-advocacy. In this workshop, it was clear that attempting to self-advocate within this system was seen as a limited strategy, and one that often resulted in apathy and disillusionment. Several participants reflected about the limited efficacy of self-advocacy: "I feel like everybody has to try and advocate at some point. But like [name] said, you could try seven times and it still won't work." One participant went so far as to say, "I just felt like the whole entire process and system, trying to go through that... it was just not worth it." Overall, there was a sense of apathy towards self-advocacy:

Going through the systems, finding your way around it, I don't know, I give up to the point where I'm like, I don't care... this is too much work, which may sound super lazy, but it's... it's annoying. I don't want to do it. It's that hard... inaccessible.

Several scholars have written about the impact of these flawed systems on students with mental health challenges. One such impact is that students will simply stop attempting to seek support if the time and emotional costs outweighs what they are able to receive (Venville et al., 2014a). Though not discussed by participants in the current study, this could lead students to drop out of university altogether. Further, it is possible that as students navigate and have negative experiences within these systems, this may create new mental health challenges or exacerbate

existing challenges. It has been noted that there is a risk that such reactions to systems may be attributed by others solely to symptoms of mental illness, which may make it harder or impossible for listeners to hear the concrete experiences of harm encountered (de Bie, 2019). As Jones and colleagues (2015) have asked, "How do perceptions of what it means to have or not have 'the same opportunities' as other community members re-shape the experience of 'symptoms?"" (p. 605). Thus, it is essential to acknowledge that the limitations of the system described have real consequences, and that there needs to be space to understand distress from systemic interactions as such. It is only through this understanding that the target for the amelioration of distress may appropriately move away from the individual and towards the system.

## Theme 2: The Relational Context of Self-Advocacy: Relationships as the Generator for Successful Self-Advocacy

Although the term "self-advocacy" implies that it is only the action of one person (the self-advocate) that determines the success or failure of a particular encounter, experiences that participants described were invariably relationally situated. In short, the reaction and response of the other person determined both the outcome of that particular encounter, and had potential impacts on that person's trajectory of accessing supports. Further, in several ways participants described that self-advocacy was only made possible or made easier in certain relational contexts. This aligns with Bruce and Aylward's (2021) proposition that claiming disability rights is "inherently relational." For instance, the provision of diagnoses and decisions of whether to accommodate someone and how are always made between people (Cox, 2017). Thus, self-advocacy relies not only on an individual's ability to explain their situation and needs, but it also relies on how the information is received and whether the listener agrees with this information

(Bruce & Aylward, 2021). Rather than the structural context discussed previously, which refers to the background in which self-advocacy takes place, the relational context was direct, front, and center in descriptions of encounters among participants. As one participant stated:

It's hard to advocate for yourself if you don't see that you fit... The motivation to fit or the motivation to advocate, even as other folks have described comes from someone being there saying, 'Yes, you can. Here's how.' And if you can't find that person that says, 'yes, you can' because you can't see or find someone like you, it's really hard to see that you can even if they say you can.

Relational Qualities Supporting and Inhibiting Self-Advocacy. Peers, professors, and service providers were all described as potentially important relationships that could support self-advocacy. Though both professors and peers each had unique features of what could make them helpful, there were several overarching qualities or roles of a relational partner in self-advocacy that were true regardless of role: the helpful listener offers practical support, acts proactively, is competent, responds in a humanizing way, and is consistent.

For relationships to be seen as helpful, practical support was desired in response to attempts at self-advocacy. All groups discussed practical support as helpful, and one participant shared of their experience with a service provider:

That was probably the most positive experience I had at UVic to date, because [mental health nurse] took the time to listen to me more than any of the counselors at UVic did, and they were able to provide me with resources on how to get a psychiatric assessment for new medications, especially because my GP at the time was resistant to the idea of changing medications.

Another shared: "She [case manager] would help me write emails and stuff and... helped me through the withdrawal process, because sometimes getting all those papers in order is really difficult." In both of these cases, students identified practical steps that were taken by the support person to help them further their access to necessary supports. Not all students had experience with such support within an encounter, though even when discussing their ideal support participants referred to having someone to provide practical support (e.g., making phone calls or referrals, providing specific next steps and contact information for the person to take) as a highly desirable quality.

Similarly, participants also discussed desiring support people who were competent and knowledgeable, and who they could trust to give them accurate and timely information. One participant described:

When I went to CAL, they gave me an academic advisor, but she just did not understand social anxiety, and so it just wasn't helpful. But with the nurse at Health Services, she had lots of experience with other students who had [social anxiety] and so she was way more understanding and helpful.

On the other side, participants shared that it is challenging, if not impossible, to advocate for oneself when the relational partner is not helpful or incompetent. Participants described that trying to get the help one needed from someone who did not have a proper understanding of mental illness or the potential supports available was futile. Not only did such individuals lack knowledge, but they were also described as unreceptive to conversation or learning from the participants' experience. Participants shared a number of stories of health professionals and professors fundamentally misunderstanding the nature of certain diagnoses or experiences, which made it impossible for adequate support to be rendered. For example, several participants shared

experiences of doctors providing inaccurate information about ADHD diagnoses (e.g., that one must have experienced childhood trauma in order to qualify for a diagnosis of ADHD). As one participant explained:

I've also had a fair share of awful doctors. And it feels so hopeless when you're in it because that should be who's helping you. And when you feel like who should be helping you can't help, it's, like, abandoning you... it's just really, really awful.

Although it is seemingly straightforward and obvious to expect that a support person will be knowledgeable and provide practical support, it is worth noting that Claiborne and colleagues (2011) found that although students with disabilities placed an emphasis on the rights and responsibilities of others to support their education, teachers placed greater emphasis on creating open and supportive relationships. Thus, although supportive and validating relationships are clearly important, as will be discussed shortly, it is essential to understand that such relationships are not viewed as sufficient without any tangible change to the quality of support received.

Participants also discussed the importance of individuals supporting them to act proactively. Specifically, participants felt it was easier to self-advocate, or that self-advocacy was less necessary, when a support person reached out to check on them, rather than having the onus be on participants to reach out and explain their situation. Although most described such proactive support as their ideal situation without having personal experience, one participant had direct experience of such proactive support:

I wouldn't have been even connected to any of these resources if it weren't for a professor specifically saying, 'I've had the same issue, and I can see that you're struggling with it,' and somewhat taking me to services, but I don't know if I myself would have done that at the time. I was just too isolated and anxious.

In this way, others acting proactively to support students had the potential to reduce the negative impact of the previously discussed mismatch between what is required of students to access services and the particular struggles they may be having related to their mental health. Proactive actions by support people can practically support students to navigate complex systems that they may not have the time or energy to do alone, and provide a source of connection and messages of deservingness that help students feel validated in accessing services.

Participants also desired relationships that were consistent and ongoing. Often describing being bounced around to different services and providers, participants felt that being able to develop a relationship with someone over time would allow for greater comfort, trust, and self-advocacy. For example, one participant described their ideal situation as, "Being able to have someone who you interact with frequently so that it's less terrifying to talk to someone new every time and be like, 'This is what I need.'" Consistency itself was seen as supportive, as one participant shared their experience with receiving more consistent support through UVic Counselling's practicum program: "It's helped my mental health immensely to be able to have somebody for a whole year [that] I can see every two weeks." This opportunity to develop trust with someone over time, whether it be a professor or a service provider, was discussed as essential, as it was seen to allow participants to feel more wholly known, and thus to receive support that was relevant to their concerns and sensitive to their needs.

All groups discussed the harm of inconsistent relationships in support services.

Participants discussed that not having ongoing relationships with support people was impactful both because they were not able to develop trust with others, and because it positioned them to always be disclosing and seeking support from different people without knowing what type of response they would receive. As one participant stated, "The idea of going to someone that I

don't know anything about and then asking for help feels a lot more scary and foreign and like they might judge me differently." Others described inconsistency in the quality of services as directly related to the support person, discussing how it often depended on which specific support person one ended up speaking with, thus making it challenging to have to switch between support people. One participant described the unique harms associated with this:

One thing that I think I am hearing, noticing, and also reflecting on is the fact is that things are just very inconsistent. And when you don't know how you're going to be received by say a professor or TA or by the counselling system, that feeling of unease just makes you feel even worse. And I think that because there are some professors who are amazing and go above and beyond, and there's... it just takes one to be nasty, or be dismissive, that immediately makes you shy away from wanting to talk to anyone and that overshadows your positive experiences. So I think just the inconsistencies and how your dialogue is received really affects how... you want to move forward with school.

This inconsistency aligns with previous research describing how responses to individuals with mental health challenges in university depend less on the overall sense of institutional inclusion and more on which particular individual a student encounters (Bruce & Aylward, 2021; Hughes et al., 2016; McAuliffe et al., 2012). This means that individuals with mental health challenges will be exposed to multiple viewpoints on disability at universities, ranging from valuing to marginalizing responses (Bruce & Aylward, 2021). Receiving conflicting messages from different support people about what individuals with disabilities deserve and the potential of individuals with disabilities can have longer term impacts on how individuals perceive themselves and their capacity and potential in higher education (Bruce & Aywlard, 2021).

Participants in all groups also discussed the need to feel humanized in interactions to be able to better advocate for themselves. As one participant shared:

It's so sad to say, but it seems like when a health practitioner is actually a kind person and goes into things... being open minded, it goes a long way. Even if they don't have all the answers, as long as they're being kind and seeming like they're gonna work with you to figure something out... I think sometimes people misconstrue what people with mental health and disabilities say... we don't need all of the answers right now, but we do need some kindness.

Some participants desired for this humanizing support to be rooted in a deep understanding not only of mental health challenges, but also an understanding of the experience of navigating complex and invalidating systems. One participant described an idealized encounter with a support person:

Just taking that time to talk to people and be like, 'your experience is totally valid...

[We're] frustrated that we need to get you to do this, but we'll help you do it... We'll do it with you to make sure that it's as easy as possible... This process that we have to get you to do doesn't invalidate... what you're experiencing and stuff because every time you get those small, even if it's just perceived invalidations, it just wears on you and makes it so much harder.

Unfortunately, experiences of dehumanization, prejudice, and discrimination were often present within participants' stories. Feeling dehumanized rendered any potential support less effective, as participants did not feel seen or cared for. All groups mentioned feeling dehumanized in the process of seeking support. Such experiences have been commonly noted in the healthcare interactions of individuals with mental health challenges generally (Livingston,

2020). One participant described this feeling in the context of over-burdened counselling services:

What I've found at the UVic Counselling is there's such a huge amount of people who are trying to access a service that you can't build a relationship with people, so it's just their job to ask these questions, and maybe offer some kind of support or something, but it's not... it doesn't feel genuine. Yeah, it just feels like you're a number... they don't have to deal with you until the next three months.

Here, it can be clearly seen that feeling dehumanized directly impacted how this participant felt able to engage in counselling. Another described a dehumanizing experience when attempting to withdraw from a class:

I was, I think, quite clearly overwhelmed and emotional and they were just like, 'you can do this or you cannot.' There's no emotional support whatsoever from that, or even like a recommendation of seeking out other support, it was just, 'Here's what I can tell you for this one request.'

This participant felt that their emotions were ignored and that all that was focused on was their practical request of withdrawing from a class. This feeling of being seen not as a whole person but as simply a person who needed to fill out a required form was challenging for many participants, who described feeling reduced from their whole, complex selves to, as the participant above stated, "just a number."

Participants also described experiencing discrimination based on their mental health.

These experiences were primarily discussed in one group, with some briefer comments made in other groups. In this case, participants described individuals making comments that were directly

denigrating towards them based on their mental health. One participant had left their program due to their mental health and was seeking to return after this leave, and described an encounter:

In the meeting with one of the other faculty members before being readmitted... into the program... this was also really hard. They were not very kind... The first question they asked me was, 'Do you really think you can be here?' And I was like, 'Yes, I do. Yes, I do.' Because I had taken two years off to work on myself. And then they also said, because I had previously worked as a lifeguard, they were like, 'I know plenty of lifelong lifeguards...' and I was very emotional during this meeting, because that was not a nice thing to hear.

Another participant described demeaning comments from a psychiatrist about their mental health:

She [psychiatrist] was asking me to describe the kind of things that I was doing when I was hypomanic, and then she started questioning, 'Why would you do that?' And I was like, did you really ask me that?... I'm being open about... this reckless behavior I was doing. She's like, 'Why on earth would you do that? Do you know how ridiculous that... do you know how unsafe that is?' I'm trying to get help. I'm... I don't want to be put in these situations.

In this way, participants described experiences where they were devalued and rejected directly because of mental health challenges they were experiencing.

Stigma and discrimination are harmful for students with mental health challenges, both in general and in the context of disclosure and self-advocacy (Lindsay et al., 2018; Markoulakis & Kirsh, 2013; Moriña, 2017; Padron, 2006; Tinklin et al., 2005). Several studies even identify it as the most common barrier faced by students (Lindsay et al., 2018; Moriña, 2017). From our

results, it is clear that previously identified common fears of being met with judgment, lack of understanding, or being viewed as inadequate for their chosen profession (Markoulakis & Kirsh, 2013) remain realistic fears. Thus, this inherently relational context of self-advocacy means that self-advocacy carries a potential risk to be harmed both personally and emotionally and academically.

When relational partners were knowledgeable, competent in providing practical support, humanizing, and consistent, participants felt their ability to self-advocate would be improved or was improved. These qualities appeared important for fostering trust, a sense of deservingness of support, and a sense that true support was available. Such qualities may help students to feel more comfortable reaching out and asking questions and more confident that there are solutions to the challenges they are facing, leading them to feel that it is worth their investment of time and energy to seek support. On the flip side, participants commented that negative interactions made it more challenging to advocate for themselves going forward. Such interactions impacted participants' sense of worthiness of help, and their belief that competent help was available to them. They also caused negative emotions like shame, embarrassment, anger, and sadness. Consequently, participants expressed reticence about trying again, especially with unknown entities. The participant who described the prejudicial interaction with the psychiatrist said, "I still have yet to get any access or services related to that mental health diagnosis and problems because of that interaction with the psychiatrist in which I just felt attacked." Another participant, in response to a negative interaction with a doctor, stated:

Basically after that, [I] just felt really discouraged and didn't push it forward because it just really fed into my imposter syndrome. So I didn't get diagnosed until this past

summer, and I didn't get an official diagnosis of ADHD until November or December of this year, and it's just so many years of school, [that are] so hard that didn't have to be.

All of this reinforces the centrality of relationships within self-advocacy. In any bid for rights and support by students with mental health challenges in university, it is thus essential to look not only at how the student approached the situation, but also how their message was received by the listener. In our workshop, we heard experiences that ranged the whole spectrum from proactive, understanding, and effective support to outright rejection and exclusion. Until helpful responses become more uniform and greater institutional inclusion is realized, relying on students to self-advocate places them in a vulnerable position to have inequitable access to supports based on who they happen to encounter.

The Unique Role of Professors. Due to the inevitable exposure students have to professors, professors were seen as capable of creating space where students could feel more aware of and open to seeking out mental health support. They were also described by participants as having greater capacity to be flexible than larger systems, for example, that they could provide accommodations to students without proof or diagnosis in the same way that larger systems such as CAL required. Finally, due to their position of power, assistance from professors was uniquely impactful as such assistance indirectly communicated the value and importance of the student within the university community.

Three groups discussed the unique potential that professors have to create safe space to discuss mental health. Here, professors were seen to have the agency to reduce structural barriers by sharing information about services directly with students. Such actions also made participants feel safer to self-advocate:

When they [professor] do their initial schpiel at the beginning of the semester, and they take the time to... do the territory acknowledgement in a proper way, and then they also have a statement being like, 'this is for CAL students, and this is the resources you can have.' And instead of it just being like X Y, Zed... they kind of make it personal... I think it's easier for me to self-advocate in that course and actually ask my professors for accommodations when I'm having a bad mental health day.

One participant also described an extra sense of safety when a professor self-disclosed their own lived experience with mental health challenges:

I think that it says a lot when a professor can self-disclose what they're going through. I think that like for people like me, I need somebody to do that in order for me to feel comfortable actually self-advocating for myself. So, there is one professor here that... she told her story to a lab group that I was working for. And then I responded to that, like I told her, 'Hey, I've been through similar things, so thank you for sharing.' And then she kind of ended up opening a door to me... she's awesome... she put a little couch in her office, she has a bunch of motivational quotes and things... She just wanted there to be a safe place for people to be able to go to... I think that's really special.

Such positive experiences speak to the potential role that professors can play in facilitating self-advocacy. Having shared experience with a professor was not limited to mental health challenges but was also discussed as being important in relation to sexual identity, gender identity, and racial or ethnic identity. Making mental health and disability visible, by speaking about mental health generally or personally in class, as our participants described, or by personalizing information and offering more than the "template" text for information about accommodations or mental health services, as others have described (Stein, 2013), can have a positive impact. Such

actions of professors not only served an informative role, but they also played a signalling role for students, letting them know that they could trust this professor to be supportive. Indeed, this latter effect seemed most important to our participants. Thus, both in our workshops and elsewhere (Fossey et al., 2017; McAuliffe et al., 2012; Stein, 2013), students felt best able to self-advocate with professors who prioritized creating safe space.

Participants also discussed how professors were able to be more adaptable and flexible that larger university systems. Both teachers and students have previously expressed the importance of flexibility and responsiveness to learning needs for offering effective support to students with mental health challenges (Claiborne et al., 2011; Venville et al., 2014a). In our workshop, this flexibility was especially described in emergency situations. One participant described:

We just had a death in my family, and... my [Department of Humanities] prof and TA were both very understanding about it, and were both like, 'well just take the rest of this week off. You don't have to hand in this thing until this time next week. Don't worry about it. You don't have to be in this class if you don't want to,' and were just really understanding about it, which was kind of a nice... A little bit [of] pressure off of everything at that time.

Another shared a story of a professor's flexibility after their mental health symptoms interfered with getting to an important class on time:

I woke up and I had a full on breakdown, because... I've never done this before. I'm freaking out. I don't know what to do. So I got my artwork, and I sped to class... And I was trying so hard to keep it together when I got there... I walked in, and I... singled out the one prof that I had a feeling might at least hear me out. And so I was like, 'Can I

speak to you in private?' and he came out to the hall. And I... didn't even go into detail because again, they don't really know the nature of my illness... So I just kind of said, 'Listen, something happened, I'm here now, will you allow me to set up my artwork and we can critique it after the break.' And he was like, 'Absolutely, you're okay.'

The ability for professors to be flexible with students as situations arose was highly valued by participants, and was a stark contrast to perceptions of interacting with larger systems in such circumstances. Where navigating larger support systems was seen as simply another source of stress for participants during emergency situations, safe and supportive professors were seen as having the power to reduce stress and provide timely and effective support to students.

Due to their position of power, professors were also uniquely impactful in their ability to communicate student value and belonging in the presence of mental health challenges. Several participants shared that, through receiving individualized support and encouragement from professors, they felt more included, accepted, and validated that their struggles were real and deserving of support. When speaking of the impact of having their professor accommodate them, one participant shared, "It made me feel a lot more comfortable with that prof at least and a lot more trusted... Because it's an online course... made me feel like more respected instead of just another name on the screen." Another participant shared an instance of speaking to a professor about their accommodations:

Normally, when I have my accommodations, I just have the letters sent out and I don't really follow up because it's intimidating going to a professor... but this time I really needed to follow up because we had an assignment that was gonna be very hard for me. And so me having to take the step to speak with my prof and be like, 'This is what I can do and this is what I can't do...' It was hard but it was also rewarding because she was

just so nice and understanding and... she didn't make me feel like I was being an inconvenience or... just taking up time for no reason. She said, 'Okay, stay here as long as you want, explain to me and I'm happy to listen to you.'

It seemed that receiving concrete academic and practical support from professors during ongoing struggles with mental health served as a powerful affirmation of the students' value and their ongoing right to an education. De Bie (2019) noted that students with mental health challenges can often feel "abandoned" by the educational system as they are "referred out" to mental health services and denied equitable access to education until they are deemed to have reduced or disappeared their struggles with mental health sufficiently. Our participants' stories clearly described the importance of being supported for continuing their academics and facilitating a sense of belonging, a finding that is consistent with other research (Hartrey et al., 2017). Thus, there is an essential role to be played by individuals in the broader university community, and not just those operating in specialized mental health services, in supporting the quality of life of individuals with mental health challenges.

The Unique Role of Peers. Peer relationships were also seen to have a unique role in supporting self-advocacy. Although the importance of peers has been noted elsewhere in facilitating collective identity, this is often coupled with caveats that peer relationships can be rare due to the secrecy and separation of individuals with mental health challenges from each other (Dolmage, 2017; Dowse, 2001; O'Shea & Kaplan, 2018). In our workshop peers were seen as unique in that offered a connection based on equality that is not possible with professors or peers. Thus, peers created open space where participants could share what they were going through, feel validated in their experience, and receive encouragement to persist. Further, peers were also seen at times as the *most* knowledgeable about how to navigate university systems, as

they had lived experience of trying to access services and encountering barriers. Similar to professors, peers, including both informal interaction and formal peer support, were seen as less structurally bound as opposed to other support services. Within our workshops, the role of peers was apparent both in explicit discussion about the role of peers and in group processes within the workshops that reflect the unique role of peers.

The role of shared experience within peer relationships was touched on by all groups. One participant shared the impact of a friendship they had developed based in part around supporting each other to navigate university systems, "It was definitely... liberating just being around someone who was also, like, struggling, but like we managed to get... through." In general, peers were discussed with an underlying sense of equality in supporting each other and figuring out how to navigate together. Another participant expressed their perceived benefits of peer support over other support services:

I feel like... involving students helping other students is maybe the best way to go. Just because I think all too often, when you go and talk to an adult, or somebody who's sitting behind a big desk, there's always this feeling of, I don't know, disconnect. And sometimes I feel like I do resonate so much more with other students who can really get it and be a lot more frank about it.

Thus, several participants conveyed that there was no professional who could fill the unique role of peers, as peers were seen as being the most relatable, and the most able to speak honestly about their experiences in university, as opposed to others such as professors and service providers who may have more restrictive boundaries.

Peers were also unique in their ability to validate and affirm fellow peers' experiences by sharing similar experiences, especially of barriers and struggles accessing services. In this way, peers were able to support self-advocacy by helping individuals understand that their struggle to access services is not because they are not deserving. As one participant stated:

It feels really liberating that I'm not in this alone... you're not the only one that has had a terrible experience. You know it does make you feel alone, it really does, when you call people and then you have a bad experience. You're like, 'am I the only person that hasn't been able to get help?'

On the virtual corkboard at the end of the workshop, one participant wrote of their experience among their peers within the workshop, "It felt validating and I felt a sense of belonging I was not expecting!" In response to the question "What's had real meaning from what you've heard so far?" one participant wrote, "Personal experiences - helps make one feel less alone in their mental health journey." In our workshop, this deep understanding appeared to support participants' abilities to feel validated in their emotional reactions to their experiences, and to externalize negative experiences, viewing them as systemic failures to be corrected.

Peers were also seen as, at times, the most effective navigators, due to having lived experience of seeking support at university. Thus, as opposed to professors or professionals, who may have idealized versions of how to access support, peers were seen to have a more realistic and nuanced understanding. One participant shared, "Because he [peer] had this experience, when I talked to him, it helped me better understand... what the process is like, and what it might be like for me." Another shared the navigational role they have played for others as a peer:

The amount of times I've had to educate folks on CAL and how they could access it and what documentation they needed... what can and can't CAL do for them has been an ongoing thing. And I think it comes as a relief to a lot of individuals when I informed them that they can access [CAL].

This role of peers in supporting navigation was also seen in the workshop, as several participants expressed encouragement or greater understanding of resources and a desire to reach out, as one participant shared, "I'm hearing all of your stories, and I'm thinking about maybe finally trying to access some different places." Similar to how professors are uniquely positioned to disseminate information, peers were seen as capable of, to an extent, counteracting systemic limitations such as a lack of clear information or confusing support structures by communicating realistic information directly that may not be accessible any other way.

Peers were also described as less structurally bound. Participants expressed a range of desires for structural changes that would result in changes in relationships such as smaller class sizes and more counsellors, but these were often viewed by participants as unrealistic and slow, if not impossible, to implement. In contrast, peer-based solutions were seen as easier and less time-consuming to implement, as they did not require the same amount of funding and institutional regulation. As one participant stated, "I think it's gonna be the connection between students that's really gonna make the difference here, because the lag between the provincial government... they don't know what students need." Another stated:

I feel like if this was just much more grassroots feeling, and coming from a very organic space, I would be a lot more open to something like that, versus if the university was, like, 'oh, yeah, we've created this new branch, we're gonna put all of these people in it, and you can come talk to somebody one on one once' or something, I feel like that's just another avenue that students would follow that wouldn't get them where they needed to go, and it would just not really fix much of the problem.

Thus, among some participants, peers were seen as having more potential to meaningfully change the situations of students with mental health challenges, in part because peer initiatives

can be less institutionally bound, and in part because the social position of peers reduced the risk of certain problems seen in other systems, such as encountering individuals with prejudicial attitudes towards mental health challenges. Overall, peer support was often discussed with a sense of hope and excitement, with several participants already being involved in peer initiatives or expressing desire to be involved in peer support. Peer support can be an important mechanism for reducing stigma, as it allows the individuals directly affected to have power to design and implement support based on lived experience, thus honouring lived experience knowledge and positioning individuals with mental health challenges as contributing community members.

The Interconnectedness of Structures and Relationships. It is worth reflecting on the extent to which these first two themes are connected. Specifically, to what degree does the structural context define or in some way constrain the relational contexts that are possible? Although not discussed explicitly within workshops, I see that there is very likely a connection between, for example, the experiences of feeling dehumanized and the overburdened nature of services, or between embedded structures that segregate students with mental health challenges from others and the perpetuation of sanism, which in turn increases the likelihood and acceptability of discriminatory interactions. Indeed, it is often through relationships with actors of institutions that structural stigma is expressed (Livingston, 2013). Further, it was consistently noted that smaller, more intimate environments, including smaller class sizes and smaller departments with fewer students, were helpful for fostering relationships. One participant described:

I came from a very small high school. And so you knew everybody in the class and you knew all the teachers and we probably had most of them the same year to year, to just being a face in the crowd basically having no personal aspect within the classroom.

This sense of being a "face in the crowd," which is nearly inevitable when navigating classes with hundreds of students and switching between classes and professors every four months, limits the extent to which positive relational contexts can be developed. Thus action towards better relationships and better structures are inextricably linked.

At the same time, this relational context is unique in that it is much more concrete and individualized than the previous theme on larger structures. Larger structural issues such as a lack of funding for mental health support and rigid diagnostic classification gatekeeping access to support occur not only within the university, but are also noted within larger systems of healthcare and disability support, impacting access to medical care, employment, and housing in addition to education (Livingston, 2013). In the face of such pervasive and harmful structures, it is possible to feel powerless and that nothing can be done. Though these structures appear largely stagnant and impenetrable, remembering the importance of concrete encounters is an essential reminder that individuals have power (even if it is somewhat limited) to act in a different way within these structures, and that such encounters can have impact. Even if the system is fundamentally flawed, understanding these flaws, communicating, listening to others and affirming their value, and helping individuals navigate makes a difference. If valued and attended to, the power to act in this way is something that can persist in spite of structural constraints.

## Theme 3: Rejecting Self-Advocacy and Imagining Caring Communities

Through participants reflecting on helpful spaces they had found and their idealized version of how mental health challenges would be viewed within university, participants imagined a fundamentally different idea of what having space for mental health challenges in university could be. For many, their vision ultimately rejected the idea of self-advocacy and

instead assumed responsive communities and services that collaborated with and had responsibility to students. Participants spoke about various components that may make such a space possible, including fundamentally different beliefs about mental distress and different structures. Such differences would allow for the true creation of space for individuals with mental health challenges in university. As one participant stated:

Anything that really pushes back the responsibility onto the person I take with a grain of salt sometimes, because it feels like a way to escape making things more accessible... I just think... having more in the way of community care instead of that push back on the individual is important.

Re-imagining Beliefs About Mental Health and Education: Capable, Worthy,

Included. All groups discussed alternative views on mental health challenges that would reduce
the need for self-advocacy and increase community participation, though groups expressed
different beliefs about what these views would be.

Participants described the necessity of a shift in beliefs of mental health challenges away from a deficit-focus that emphasized lack of capacity and unworthiness of help. As one participant stated:

I feel like a lot of people have this assumption that people with physical and mental limitations can't be productive members of society, and it's really frustrating, because we are... definitely able to be everything that people who don't have physical and mental limitations can be... I feel like without that assumption, then we wouldn't have to advocate for ourselves.

The opposite of this, believing in the potential and value of students with mental health challenges, was perceived to potentially lead to greater investment and positive supports to

ensure the potential of such students is fully realized. One participant articulated what such an alternative view would look like, indicating they wished supporters would say:

'This is not going to be the thing that stops you from getting somewhere,' and trying to have it be like very positive and saying, 'you have goals, you can go for them. You just have to take maybe a slightly different route to somebody else, but that doesn't make your journey any less important or any less valuable.' And trying to make it less about whatever it is that is making things difficult and putting a spin on like, 'Okay, well, what can we do to make this awesome,' and trying to make things as optimistic as possible, because I think all too often it's like, every time I have to go into a space where I have to talk about my mental health, it's exhausting. It makes me feel like crap. It doesn't make me feel uplifted. It doesn't make me feel excited. And I think trying to almost flip that narrative would be really awesome.

Throughout the workshop, participants described how scarcity narratives and being met with skepticism by professionals further contributed to a lack of perceived worthiness of support. For example, one participant shared:

I know I'm not alone in feeling like, 'Oh, you're just not deserving.' I think that's the biggest thing is this major feeling of imposter syndrome and that you're taking away from other students who may need it more. And you're always comparing yourself to others.

Several participants agreed with both receiving and internalizing the message that they needed to evaluate whether their suffering was "bad enough" to warrant access to limited services.

Consistently, participants reinforced that they would want themselves and others to feel secure in deserving support. Though increased availability of services was one way to remedy this,

participants also identified beliefs and hierarchies of which mental health challenges are more "severe" and "worthy" as contributing to this sense of impostor syndrome.

Both through discussion of university culture and through personal stories, participants portrayed that the culture of prioritizing academics at any cost contributed negatively to their ability to reach out and receive support. As one participant described, "I had a really big depressive episode and I had to be hospitalized for it. And one of the main concerns I had was... I have a midterm in two days." For several participants, it felt like a failure to seek support because it was perceived to indicate that the person was prioritizing their own wellbeing over academics. This was felt to run counter to the culture of university. Thus, shifting university culture to be more balanced so that it made space for students to pursue other important goals, including mental and physical health, financial stability, relationship responsibilities, and so on, was envisioned as necessary to shift responses towards students with mental health challenges.

Although less-commonly discussed, several participants expressed a desire for less segregation of individuals with mental health challenges from other individuals. They felt that drawing distinctions between those with mental health challenges and those without fostered negative and exclusionary attitudes. As one participant shared:

Something that I don't want to see be created is either information or resources which further promotes the division between... students who have a disability, and those who either choose not to disclose or who don't have a disability, and which results in people... negatively seeing people who access those resources as gaming the system.

Another participant noted that, not only does this othering result in negative attitudes, it also reinforces the separation of disability from normal life, stating, "I just wish we understood that most people have something... and just treated it like part of the process." The problematic

segregation of support (e.g., accommodations) for students with mental health challenges has been noted elsewhere as reinforcing the exclusion of disability from societal life, relegating disability to a special case requiring special treatment (Kruse & Oswal, 2018). Others have argued that this segregation is additionally harmful as it results in one-by-one adaptation and accommodation to structures that may be inaccessible to many individuals, thus resulting in accommodation only for the privileged few who can gain access (Dolmage, 2017; Venville et al., 2014a). Thus, a shift in beliefs towards assuming that disability, including mental health challenges, is present in university would necessitate an accompanying shift toward environments that are accessible for such individuals. Such accessible environments would be the norm, rather than "special" environments where individuals with mental health challenges must go to receive supports.

Re-Imagining Mental Health Support Structures. Participants had many suggestions for improving accessibility of university structures. Often, participants' first response to questions about changes to better support students was "hire more counsellors." Participants described how greater availability of support workers would result in greater capacity for outreach and proactive support, better interconnections between services, more dedicated time to support students to navigate supports, and services that had capacity to both support wellness and mitigate crises. Such suggestions align with calls for a more supportive, responsive, and preventative approach to supporting students with mental health challenges (Chang et al., 2020; McEwan & Downie, 2013). Participants also described a variety of structural changes in university that would support the potential for community care, including opportunities to be in smaller group settings, and greater flexibility, transparency, and accountability.

Participants desired services that would have the capacity to engage in outreach and proactive support. As one participant envisioned, "I wish that... these services would go to people rather than people having to go to them." Some participants imagined an option for students to easily request contact with services via a brief online form. Another participant described an experience of outreach they had at another college that was impactful for them:

At [college name] they had a women's building or something. And I had never been... didn't even know it existed, but then my [teacher] was like, 'they have free juice boxes today'... So then I was like, of course I'm going to go get a free juice box. So I went to get a free juice box, and then... that got me there... and then you're just there to get the juice box, so there's no pressure to divulge, especially if it's a mental health thing. If you're having a really good day, sometimes you don't really want to, I guess, out yourself as someone that needs help. So, it's almost easier to have that out that's like, 'Oh, I'm actually just here for a juice box.' But secretly, I'm very happy that I'm here, and now I know where it is, and now I'm scoping out the situation, and I can see that these people look like they want to help me, and it's a nice environment. And that's a mental note for the future that I can come back here and it's a safe spot for me.

Several participants discussed this desire to have more informal environments where they could learn about services and meet service providers without feeling pressured to disclose information or immediately seek support. Such efforts were seen as important for building trust and comfort so that when students did need to access services, the process would be less overwhelming and foreign.

Participants also felt that a greater capacity of support services would result in timely support. Within support services, participants described that being able to talk to someone

quickly helped to provide a sense of action and a sense that solutions were possible. As one participant suggested, "Just being able to talk to someone immediately... even if they can't provide you with answers, just to kind of send you in a direction." Another participant described the sense of belonging and worth that is conveyed through immediate support:

The fast response times thing, feeling like you actually matter, somebody else was mentioning that you're not just a number. Because I think that can definitely... just [make] you feel like, okay, you did the right thing by asking for help.

Thus, participants discussed immediate support as not only more effective, but also as connected to communicating an institutional culture that values students with mental health challenges and treats such students in a humanizing way.

Relatedly, participants also desired support services that were focused on providing ongoing support and promoting wellness, in addition to crisis-oriented support.. The opportunity for ongoing support was also perceived to help mitigate crises, which was seen as both supportive of students and effective for services. As one participant stated:

Things that are more upstream in supporting wellness, rather than just mitigating crises as they occur, are far more supportive to individuals. If you start early, and actually build that foundation of wellness, then you're... not having to quite do so much pulling people out of these huge holes that they fall into, or that they fall through the cracks and have to climb back out of that, which takes a lot longer and a lot more resources.

Developing greater interconnectedness of services was also seen as essential for supporting self-advocacy. Participants desired greater interconnectedness with services, both in making clear referrals between services and in sharing information easily so that it did not fall to

participants to go on a "goose chase" to inform different professionals about their situation. As one participant stated:

Having a better communication system between them in order to... be able to very easily just be like, 'Okay, we'll just transfer you to the next line for Health.' Or just instead of... the student [having] to go through multiple steps, just to have them be able to do a lot of that for you.

Such streamlining of system navigation is more aligned with the identified needs of individuals with mental health challenges since, as discussed previously, the nature of certain mental health concerns means that individuals can have difficulty following multiple complex steps and/or having the energy and motivation to navigate such systems. Thus, interconnectedness would improve accessibility of systems.

Workshop groups also discussed a desire for someone with knowledge of the complete range of support options to talk through options to determine what services and supports may be most helpful for them. Groups discussed that having time within services to work through necessary components of accessing services, such as paperwork and contacting various services, would be of great benefit. Though most participants discussed this as their ideal circumstance without having personal experience, one participant described an experience they had with a service provider at the university:

The person who [was] there was so helpful, they talked through my options with me and gave me advice and looked [up]... a place to go to get a quick diagnosis which you have to pay for out of pocket... and [they said] you can apply for grants for student loans when you have an official diagnosis... it made the whole process quick and they just they did a

lot of the work for me. It was so helpful and now I have a diagnosis, which was so validating... means that I can get accommodations and seek treatment.

Essentially, there was a sense of wanting services that worked *with* students to access the supports they need, and to consistently support student access, as opposed to referring students in loops to different services which may or may not be relevant.

Re-Imagining University Systems. Beyond changes to specific support services, participants also envisioned changes to overall university systems that would be supportive for students with mental health challenges. These included having the opportunity to build relationships in smaller settings, greater flexibility within university services and academics, and greater transparency and accountability.

Participants who had experiences in smaller settings, whether it be smaller colleges, smaller programs within the University of Victoria, or smaller class sizes, described having more positive experiences than participants who experience larger academic settings. One participant compared their experience in small classes to large classes:

The profs that I see for my [Department of Fine Arts] classes, we build more of a rapport than, for instance, a prof in a lecture class, where I don't ever talk to them really other than to show up and sit and listen and then leave. So I don't know if I would feel comfortable ever going to one of those profs for help. Because I don't have that established... trust... I'm just a student in their class that they've never talked to.

Overall, within smaller programs at the university, students described connections with staff within their program that supported proactive and ongoing support that required less interaction with university bureaucracy. Another compared their experience with disability services at the University of Victoria to what they experienced at another college:

I had a very easy time getting registered at [college disability services]. And I don't know if it's just because [college] is a smaller institution. There's more of an intimate feel. You don't feel like you're one of a million... you're humanized in some sense.

Thus, participants ideally desired smaller class sizes where students could build trusting relationships with their professors and peers. Such settings were seen to make other services less necessary, as they would allow for professors to have more time to spend with students and design course content that meets diverse student needs.

The massive expansion of student attendance in higher education without a concomitant increase in funding poses barriers for students with mental health challenges in university (Tinklin et al., 2005). Although the expansion of student numbers and class sizes arguably negatively impacts all students, this may particularly impact students with mental health challenges. For instance, such increases may relate to rising demands on student support services. Increases also contribute to reduced consistency of relationships, as large numbers of students may render instructors distant and inaccessible, and reduce the likelihood of interacting with consistent peers (Tinklin et al., 2005).

Participants also felt that greater flexibility embedded within university would be more supportive of students with mental health challenges, including flexibly of service access through CAL and flexibility with learning opportunities that allow students with mental health challenges to participate and succeed without unduly impacting their mental health. Offering such flexibility was thought to be closely connected to shifting beliefs around individuals with mental health challenges. For example, if individuals with mental health challenges were seen to be honest and capable, then, diagnosis would no longer be required to prove the validity of their struggles. As one participant described:

Just because I haven't been able to get a diagnosis does not mean I don't struggle with those problems just as much as people who have the diagnosis. And I don't know exactly how [CAL] would do this, but maybe just having a system which would have a doctor or a therapist or psychologist advocate for you and [say] that, 'This isn't an official diagnosis, but this is something that we have been working on with this person, I think it's fair to assume that they could use the help the CAL has to offer.'

Another described experiences in her smaller program where her needs were adapted to via program flexibility:

It was the program itself being very understanding or being very non-punitive, being very accommodating to my needs, helping me adjust times to take exams and things like that, and trying to find... something slightly different... for my [practicum] placement.

Thus increased flexibility was seen to be a beneficial addition to existing systems, such as CAL, and an opportunity to reduce the need for services such as CAL if programs worked with students more flexibly to meet their needs without requiring proof of diagnosis or formal registration. Such flexibility could also reduce the segregation of students with various disabilities because it anticipates and plans for diverse needs as opposed to beginning with a one-size-fits-all assumption and reacting each time this assumption is disproved (Hibbs & Pothier, 2006).

Greater transparency within university systems was also desired. When participants expressed frustration towards services, part of this frustration arose from not understanding why certain systems operated as they did. This at times resulted in participants feeling patronized or like they were not able to adequately advocate for themselves because important information

about how services worked and why was being kept from them. One participant described wanting:

More details, more guidance and detail of how... they organize things, so that we can better understand what it's like from their perspective. As soon as I'm able to see what it's like someone else's perspective, I have more compassion or empathy, like how to deal with why is it taking so long? And I feel less frustrated, because I understand why this is difficult, or why there's wait times.

Participants discussed that such transparency may also help their path through university feel more predictable and prepare them for, for example, the length it may take to get registered with CAL, as opposed to being surprised or disheartened by encountering barriers or time delays.

This desire for greater transparency reminds me of a "Battleship" metaphor used by Dolmage (2017) to describe how university support systems operate currently. In its current form, students are positioned to throw information over to support services and hope that they "hit" on the right service or support at the right time. Greater transparency would allow students seeking support to be able to see their opponents' "Battleship board" so that they can make more informed decisions about which paths to take and understand the reasons why they may "miss" receiving adequate support. Further, participants communicated that transparency also conveyed a greater sense of respect for students, because it communicated that students are not adversaries to be kept out of over-burdened services, but rights holders who deserve access to information on how the systems that impact their lives work. Therefore, transparency was seen to have the potential to foster more collaborative relationships between students and support services.

Finally, participants desired a system that had mechanisms for accountability and adaptation. Accountability was especially desired when students experienced maltreatment from

professors, such as being denied their accommodations. Though such systems of accountability ostensibly exist, in practice the process of making a formal complaint is often burdensome and delayed (Palmer, 2000). By the time accountability is enacted, students have already been negatively impacted by not having access to their rightful supports and by having to spend valuable time and energy pursuing a complaint. One group suggested that Teaching Assistants could advocate for them if, for example, professors were not honouring accommodations:

They're [teaching assistant] also a witness for the class... an unbiased witness for if the prof were to ever do something unfair or do something that you would think would be unfair, you would have a trusted observer for that kind of interaction to advocate for you in the future.

Workshop participants desired a variety of feedback mechanisms across university systems, including suggestion boxes, places to offer feedback about disability sensitivity of professors in course evaluations, anonymous surveys sent out to students who discontinue counselling, and a more effective Office of the Ombudsperson. Importantly, accountability required a shift in power, both by taking students seriously and supporting them when they had been harmed by negative experiences at university, and by actually reviewing and implementing feedback and suggestions.

Having The Space: The End Goal of Change. The end vision of all of these changes, both to beliefs and systems, was to render mental health challenges a visible and important part of the university community. Essentially, participants discussed wanting the exact opposite of structural exclusion, by describing opportunities for full participation, belonging, and inclusion. In this desired future, participants envisioned that there would still be specialized services and supports for mental health challenges, but everyone would have a responsibility to support

students with mental health challenges. When discussing the role specialized mental health advocates might play, one participant pointed out, "I guess, also trying to have everybody be an advocate. So, like professors, and the people at the Student Wellness Center... they're all advocates, or they should be." When imagining what having space for mental health at university would look like, this was sometimes discussed literally, in terms of visible, open, and adapted space, as well as more metaphorically, in terms of the university conveying awareness of the full spectrum of mental health challenges and having space within relationships to support people with their specific needs.

Several groups discussed that the creation of visible, accessible physical space would reduce the need for self-advocacy among students with mental health challenges. Their idealized university was a direct challenge to the current invisibility of students with mental health challenges on campus (O'Shea & Kaplan, 2017), where disability is often briefly eluded to at the end of a course syllabus but otherwise ignored (Dolmage, 2017). Several groups discussed physical space that was adapted in certain ways, such as having sensory rooms where students could go to relax and regulate within the university campus, and adaptation of spaces like the gym and the library to be more conducive to individuals with mental health challenges (e.g., quieter, softer lighting). Others discussed having resource centers more visible on campus as a means to improve accessibility. As one participant stated, "I really liked the idea of resources being easily accessible in terms of physical spaces on the campus, because... out of sight, out of mind for me. If something is not visible, I will never remember it." These spaces would serve the important function of making the presence of mental health challenges more visible on campus, thus creating the sense that students with mental health challenges are considered and included on campus, and addressing practical accessibility of support. This is a clear indication of desires

to move beyond accommodating mental health challenges in inaccessible spaces to designing social and institutional spaces with students with mental health challenges in mind (Kruse & Oswal, 2018).

Having the space also meant having visible acknowledgments of mental health struggles, whether that be through posters or communications with the university or within classes.

Participants discussed how this would not only improve accessibility and knowledge of services, but also normalize the existence of mental health challenges within university. As one participant described

Occasionally I see stuff like that posted up, and when I do see it, it does make me feel better. But I feel like if it was more normalized and, in very general places, [I] feel like it would be really helpful, just because then you'd have the whole student body seeing it all the time... For a lot of people I think they'd feel more seen and be like, 'Oh, wow, there is mental health resources here... I'm maybe not the only one who struggles with this.'

Participants discussed how existing information on mental health at the university is often sanitized, addresses mental illness superficially, and focuses on more mild forms of distress. One participant discussed wanting to see representation of more impactful struggles with mental health, stating:

Not just talking about like the fluffy, happy pieces of mental health, like self-care and self-love, it's like, making sure that students also know that if you're in a dark place, and if you're in a bad place, there's also resources for that, and that's also important... not just having self-care, meditating things, because... that is helpful to an extent, but... as a person who struggles with mental health, when I see stuff like that, I'm like, that doesn't seem like it's necessarily made for me... [it] feels like it's made for people that are

neurotypical to have a better understanding of self-care... but it's just kind of like, what if you really are struggling?... It feels like [the university] sometimes kind of [tries] and shove[s] that... away sometimes, which I understand but also it's a reality that a lot of students deal with. So, why are we hiding it?

This important comment highlights how mental health discourse at university has the potential to exclude and marginalize those who struggle the most with mental health challenges. Euphemistic language such as "wellness" and "Access Services" can erase the reality of disability and struggle, and imply that students should be thriving and well (Dolmage, 2017).

Even within the current system, participants wanted the university to acknowledge the lack of space that currently exists. Two participants argued that part of what makes existing barriers so challenging is the lack of knowledge among faculty, staff, and health professionals that such barriers even exist. This ignorance presumes that services are available, and if students struggle to access those services, then the students must not have tried hard enough. In this way, it appeared that not only was there no space for mental health challenges on campus, but there was also no space to recognize and acknowledge that there was no space. Participants expressed a general desire for more awareness of what it is like to be a student with mental health challenges. For example, one participant stated that they desired, "a general understanding from profs that maybe if you are trying to access CAL, and you just can't get in there... that they know it's a process so maybe education on their part too." Although seemingly small, this desired shift towards a broader understanding among the university community about the experiences of students with mental health challenges may mobilize systemic change, because part of problem is that participants perceive that others believe systems are working adequately.

Although not explicitly discussed, something that was central in these discussions was that participants were not describing one foolproof formula for how to help students with mental health challenges to succeed. Instead, participants often had differing opinions in describing what types of supports and learning environments were beneficial for them. For example, some wanted to be connected with services largely by information they could find and apply independently, whereas others desired support people to walk them through their options. Some discussed finding more generalized services helpful, whereas others desired specific support (e.g., based on diagnosis or identity). Some wanted greater access to certain services, such as counselling or psychiatry, whereas others wanted greater access to more informal support in the university community, and some wanted both types of support. Some felt strongly that online learning supported their ability to engage as a student with mental health challenges, and some felt online learning greatly harmed their ability to learn. Thus, "having the space" did not mean trying to find the one correct solution to supporting individuals with mental health challenges. Rather, it meant cultivating multiple forms of space so that students could choose the options that make sense for them. This evokes the concept of universal design in learning as applied on a larger scale within university systems. The principle of universal design calls for the development of multiple paths to an end goal, in this case, a university degree. Thus, rather than there being one "right" way to move through university as a student with mental health challenges, there are multiple paths and fewer "wrong" ways, even if these multiple paths are seemingly redundant (Dolmage, 2017). One example of how this may exist in practice involves greater integration between services: a student enrolling in CAL may also at that time have the chance to explore with someone in CAL staff which other campus services may be relevant to them, and be connected by CAL to those services. CAL is just use as an example here, but for

universal design, a similar model would be used across services so that, no matter where one starts, structures are designed to help get the student where they need to go for the assistance that is most relevant to them. In listening to participants, such redundancy seemed essential to allow for participants to move through university and associated support services in a way that was accessible and made sense to them, as following even the most dominant or common opinions of the needs of students with mental health challenges may exclude and marginalize those who are most in need of support.

#### Theme 4: Rejecting Self-Advocacy: The World Café as Catalyst for Collective Constructions

As can be seen through both the structural and relational contextual focus of self-advocacy and the description of a re-imagined caring community, participants described their experience as rooted in their environments, as opposed to at the level of individual skills or abilities. This important context affirms the idea that stigma must be shifted through transformational structural change of those structures which permit and promote inequity and injustice, as opposed to efforts which target individual attitudes and beliefs. Although undoubtedly related to the focus of our workshop, which was explicitly structural, it is worth noting that even when we did ask questions that were more oriented towards individual solutions, some participants struggled with the ethics of answering such a question. Participants spoke of qualities such as assertiveness, outgoingness, patience, and determination as supportive of their self-advocacy, but some expressed discomfort with the idea of students with mental health challenges needing to cultivate certain personal qualities in order to receive support. As one participant stated:

I really hate recommending... persistence is probably the most important thing you need.

But, I don't know... it feels a little bit like part of our goal is to require less personally out of people to have to be persistent on their own.

Thus, what I heard from participant discussions was a desire to expand the responsibility to individuals with mental health challenges outside of these individuals themselves to a wider range of relationships and structures, as opposed to the current circumstances which were piecemeal and often appeared to treat mental health challenges as a burden and an afterthought.

Although the picture painted by participants of university life as a student with mental health challenges was bleak and the feeling within the workshop was at times demoralizing, at others was exhilarating and encouraging. Specifically, there was a certain exuberance that came from participants discussing shared experiences and from being able to identify systemic barriers and potential solutions together.

The value of discourse among peers to externalize challenges within university was well-captured on participants' post on the virtual "corkboard" that was set up at the end of each workshop session. Several participants wrote about the value of shared experience within the workshop, reflecting on the question "What's had real meaning from what you've heard so far?" with responses such as "Knowing that I am not the only one who has experienced real struggles with accessing support systems within Uvic," and "I'm really glad I found out just how common it is to have these problems with the university." When participants were asked to reflect on what they most wished others could learn from the workshop, several posted comments reflecting their desire to support others to recognize systemic failures and cultivate their own sense of self-worth:

You deserve to be here. You deserve to access a university education despite what you are experiencing in terms of mental health. You DESERVE support. Lots of love to you all for trying your best to navigate a system that doesn't support you.

Another participant wrote, "That struggling and having mental health/disability challenges does not mean we don't add to or contribute to our classes and that we are capable of doing things when our needs are accommodated." Others responded to this prompt with statements that more directly challenged the existing system: "That mental health shouldn't be a barrier to education and that we deserve more support and accommodation," and "The systems are set up with an ableist mindset and doesn't really consider accessibility or diverse student needs." In this way, it appeared that this group environment was particularly well-suited to cultivating a sense of solidarity and an ability to name the causes of struggle as systemic, rather than individual.

Individualistic interpretations were the exception in the current workshop. This is of particular interest to me as individualistic discourses are commonplace and often more institutionally supported than those that push for system accountability. For example, previous research has found adherence among individuals with mental illness to such discourses, such as homeless individuals in Ottawa who felt that "blaming the environment," or accounting for social, historical, and cultural factors to be "making excuses" (Dej, 2016). Thus, I offer several explanations for what allowed for an environment where systemic, as opposed to individual, discourses were fostered.

The first and most obvious explanation was that this workshop was explicitly focused on structural barriers related to self-advocacy, rather than being a workshop to talk about how important self-advocacy is. From the outset (e.g., recruitment materials, pre-meetings with participants), this workshop was situated as one where self-advocacy was a problem, not a

solution. This likely drew for participants who constructed their experience in a similar way and allowed for a focus on experiences of barriers.

Further, participants were from a range of age groups and educational trajectories, including some individuals who were older who had either already graduated, had left and returned to school, or had started school as a mature student. These participants in particular told stories that reflected an evolution in their thinking towards an externalization of systemic failures, as opposed to internalized beliefs of limited potential. These stories, and these participants' reflections on more junior participants' stories, may have supported co-construction of experiences as systemic failures. Besides the role of specific participants, the overall role of being in a group was likely essential in this development. As participants found commonalities and shared struggle, it made little sense to describe such failures as internal, because participants could see that there were patterns in how systems were failing.

Finally, it is notable that all of these participants were either current or former university students. University can play an important role in empowerment, and can help individuals to learn about different perspectives (Dolmage, 2017; Jones & Brown, 2012; Knis-Matthews et al., 2007; McAuliffe et al., 2012), and, indeed, some participants discussed their educational backgrounds influencing their view on the causes and consequences of their own struggle. Thus, this systemic focus may also have been related to the knowledge base and social position of these participants.

Regardless of the reasons for this focus on systemic failure and rejection of self-advocacy on the part of participants, it was clear that participants felt this focus was a valuable rerendering of experience. In this sense, it felt as though hermeneutical injustice was being challenged within the workshop (Fricker, 1999). As participants discussed their experiences and

reflected on changes that were needed within the system, it became clear that they were creating an understanding of their experience that was different than the dominant perspective. Rather than believing they were incapable, "exaggerating," or undeserving of support, many participants targeted their anger, and their hopes, towards the system. Although some participants entered this workshop with this lens, several reflected on how this interpretation was something they developed over time. As evidenced by the corkboard comments shared above, participants felt this narrative had value and wanted to share it with others to help re-construct experience. In this way, the social construction of self-advocacy narratives and solutions differed fundamentally from dominant ones: rather than viewing self-advocacy as the key to success, as perpetuated by larger institutions, participants rejected this narrative and claimed their role as valuable members of the university community who are inadequately supported. As one participant wrote on the corkboard:

Our limitations don't define us and they do not inhibit us from succeeding in a university setting, what does however inhibit us is the lack of supports needed to be successful and the lack of accessibility to those supports. And that is not our fault. This is a systemic failure. Not a personal failure.

# Working in the Context that Is: Recommendations for Supporting Navigation and Advocacy within the Current System

To close this section, it is important to discuss that participants also shared shorter term changes that would help students with mental health challenges to better navigate the system as is. This section differs from the previous as it is action-oriented to provide immediate and direct recommendations for change. Given that this theme is action-oriented, within my analysis and

presentation here I am focused more on the actual content of what people said (i.e., what specific suggestions for change were made), as opposed to the underlying meaning of these suggestions.

Layered and Centralized Content. Participants wanted access to information that is layered and centralized. In terms of centralized information, one participant stated

I find a lot of times things that are similar at the UVic website are all in slightly different places. And so to have it all into one... big amalgamation of mental health or physical health, or whatever it is, I think would be very helpful for people to better navigate that. Several participants commented on navigational information being challenging to find due to its separation across various websites, making it both cumbersome and challenging to find the information and challenging to understand services in relation to each other (e.g., understanding what the role of CAL versus the Office of Student Life versus the Counselling Centre is). Several participants also pointed out that they wanted this information to be layered; rather than be inundated with complex information, participants expressed a desire for brief information with clear steps to acquire more information in the areas the student is interested in. For example, one participant stated:

I think like the emails could be formatted better, and maybe like bullet points, and within those bullet points, there are hyperlinks leading to like the website where you can find more information. So that way, [you] still know these things exist. And if you want, you can find out more.

A few participants discussed desiring this resource to contain information not only about services but also about the barriers to services, so that students can be prepared for and knowledgeable about how to navigate various roadblocks that may arise. Other key information participants desired in this centralized resource was contact information for services, information about what

is required to access supports, and information that portrays empathy and inclusiveness.

Participants discussed several forms this information could take. One of the most requested forms was a map of campus containing this information, as this would also embed information about where on campus to find services. Others suggested this information take the form of a pamphlet.

Information in Multiple Accessible Places. Participants highlighted that where the information is currently housed on various parts of the UVic website is not user friendly. Participants also expressed that information on social media was not always helpful, as not everyone has equal access to social media and it can be challenging to find the information again if one wants to go back, and that information in syllabi was not helpful as this was not seen to be a place students will look during a crisis. Participants discussed multiple places they would find information more accessible. Importantly, participants expressed desire for this information to be available in multiple of these different spaces. The most suggested place for information to be available was a separate tab on BrightSpace, UVic's Learning Management System. Participants discussed that this would be an accessible place as all students regularly use BrightSpace and need to know how to use it, so it would not involve learning to use a new tool. Participants also discussed the value of having regular emails reiterating information sent out to all UVic students. In general, participants expressed that they did not want to hear about the information only once, but wanted regular reminders that support was available. As one participant stated:

I like the idea of having it be not just an email that you get at the beginning of the year because there's usually a lot going on... that wouldn't be on the top of my list of things to look through or to do. But if it came like three weeks into the semester, then I might be ready to look for that.

Participants also discussed announcements in classes and physical reminders of resources (e.g., posters) as important means of reiterating information. Having this information available to students early was also seen as important, with participants discussing easy access to information at students' initial orientation, upon acceptance, or even earlier when individuals are applying to UVic so they can determine whether resources available will meet their needs. Such desires for more accessible information were similarly expressed by participants in Study 1 of this dissertation, with several similar suggestions for accessibility (e.g., BrightSpace, visible postings around campus), affirming the appeal of these solutions for students.

**Personalized information.** Several groups discussed the potential usefulness of a brief online course about UVic resources where students could interact with and learn important information. Two groups discussed the idea of a survey students could complete that would give more individualized recommendations for services. Specifically, one participant described:

Having some sort of quiz that is like, 'Based on your answers, we think this service could potentially be helpful to you, but here are a few other ones that you might also want to look into.'... Just narrowing it down for people.

Other groups discussed accessing personalized information through physical resource hubs where students could go to ask a trained person questions about the resources available and their various options for support. This aligns with suggestions made by participants in Study 1 of this dissertation to not only have broad information, but to have information that may be specific to students' unique situations. Participant comments in the workshop add on to this by explicating specific methods by which such tailored information could be made accessible to students.

**Personal Qualities.** Beyond specific information to support students' navigation, participants discussed personal strategies and qualities that supported their ability to self-

advocate, and what advice they would give to students in their same situation. Importantly, several participants offered advice, with the important caveat that they wished there was less required of students in terms of personal and relational qualities to access rightful supports. That being said, participants discussed qualities regarding their relationship to themselves, relationships with others, personal qualities, and interpersonal qualities that supported their self-advocacy. First, participants emphasized the importance of cultivating a positive relationship with themselves, specifically in terms of self-confidence and self-worth. Within the current system, this was seen as essential because of messaging students might receive that invalidated or minimized their experience. As one participant advised, "You do deserve the access to these resources... If that's a problem that you have, you're allowed to take the help that's being offered to you."

Participants also discussed the role of a positive support network, including the key role of friends, family, and partners in assisting them accessing supports. These relationships were seen to at times offer practical support, help validate the person's experience, and encourage feelings of deservingness from an external source. Speaking of practical support, one participant shared:

I was also a first generation student, and my parents don't know anything about this process. I think all of the services that I have accessed at the university has only been because my sister went to UVic and accessed those services. I don't know that I would have actually had the ability to figure it all out.

#### Another participant advised:

I feel like having a relationship with someone who's going to encourage you to advocate for yourself is really important. At least it was for me, having a friend or... a significant

other be, like, 'You should get help, you deserve to get help. This is something that you should do for yourself'... Just an encouragement that it's telling you that it's okay to advocate for yourself, and it's okay to get help.

Participants also discussed personal qualities that supported their self-advocacy. The most discussed qualities discussed by participants were persistence and assertiveness. One participant advised, "Don't take no for an answer. You're allowed to say, 'that's not enough.' You're allowed to say, 'I appreciate that, but that's not going to work for me." Such persistence and assertiveness were seen as essential for getting one's needs met in a system that was perceived to be designed to keep people out of services. Participants also mentioned the importance of patience, with some reflecting that they needed to see their journey to accessing support as a multiple semester undertaking that would benefit them in the end, if not immediately. Participants also discussed the importance of being knowledgeable about services and individual rights, so that students could feel confident in speaking up for themselves. Part of this was being knowledgeable about barriers as well, and expecting obstacles, so that one does not become disheartened by the process. One participant shared what they might say to a student asking them for help, "Expect it to take a while... Come back to me in a week or something, and let me know what's happening, and we can keep troubleshooting. Because it's gonna... suck. But there is a way to do it."

Participants also discussed interpersonal qualities utilized when interacting with service providers to improve the chances of success of advocacy. Participants described being friendly and pleasant as important for getting their needs met. One participant described their emails to service providers as, "There's so many exclamation points, oh my God, I feel like I'm yelling the whole time. 'Thank you so much. I really appreciate it.' Just trying to be [open] to them so that

they're more open to me." This aligns with Dolmage's (2017) assertion that requests for rightful disability assistance in university are given the "tone police treatment," where students are expected to be grateful and positive when receiving such supports, sometimes as a prerequisite for actually receiving support. Participants also recommended being clear in their communication, and responding quickly to communications to keep processes to access and stay connected to services going. Interestingly, there was a split in participants where some participants expressed that being open and vulnerable in their relationships with service providers helped them get support, and others felt that being vulnerable led to them not being taken seriously and being denied support.

Thus, although the current system was clearly labelled as insufficient and flawed in several ways, given the rigidity of current systems, participants had creative and clear ideas for how they could be better supported within the system that exists, and advice to give to students to become more adept at navigating the system. Such suggestions are important to attend to, as they suggest relatively quick interventions that could improve the educational experiences of students struggling right now. This aligns with ideas that community researchers need to balance focus on comprehensive social change with more urgent and smaller local changes, with researchers in particular being at risk of ignoring short-term solutions and favoring longer term social change (Reason et al., 2011).

### Summative Discussion: Self-Advocacy Narratives as the Machinery of Inequality

The narratives of participants in our study captured the complexity of self-advocacy.

Although students often did make attempts to advocate for themselves, these attempts were invariably structurally and relationally situated. In short, the results of self-advocacy depended on the person to whom participants were advocating and what support was possible within

structural constraints. Participants were clearly aware of this, and thus many participants rebelled against the idea of self-advocacy as inappropriately centering their own responsibility for receiving support when they were keenly aware of the structural limitations of support structures. Although a small number of participants described positive experiences of advocating for themselves and receiving helpful and consistent support, many shared stories of spending a good deal of time and effort trying to access support, only to find out that the level of support they required did not exist, to be turned away from support, or to experience support in a relationshipby-relationship, piecemeal fashion. Leaving the workshops, self-advocacy as a strategy for navigating complex and over-burdened systems felt futile. Although I expected to find selfadvocacy was problematic because it places the onus of responsibility for seeking support on individuals who are already struggling (Fossey et al., 2017), I was surprised to find the additional layer that self-advocacy was also problematic in that it implies the possibility that each student can get the support they need if only they navigate the system just right. After hearing participant descriptions of the state of systems intended to support individuals with mental health challenges, I was left with the (mostly rhetorical) question "What are students supposed to be self-advocating for?"

Thus, it seems clear to me that self-advocacy narratives as they are perpetuated by higher learning institutions are just one gear in the "machinery of inequality" (title; Tyler, 2020) that excludes and marginalizes individuals with mental health challenges in university. Here, self-advocacy narratives can also be seen as a form of structural stigma, especially given the extent to which they appear to be embedded in institutional practice. Basically, self-advocacy narratives appear to function in such a way as to imply that, if a student with mental health challenges is not able to access the necessary supports, then that is the fault of the student and a mark that they are

not ready or do not belong within university. Combining this idea with the observation of participants in this study that existing systems are simply inadequate to support their needs due to being under-resourced, out of touch with the needs of students, and inconsistent, it is clear that self-advocacy narratives individualize what are, in many cases, systemic failures (Cox, 2017). Such individualization may allow for higher-level justification of continuing to socially exclude and unequally distribute resources towards individuals with mental health challenges (Tyler & Slater, 2018), as failure of students with mental health challenges can be constructed as an individual lack of capacity, rather than a sign of a failing system.

As was seen throughout the analysis, self-advocacy narratives can also be seen as ableist to the extent that they assume the presence of skills and abilities which are, in some cases, the exact areas of ability in which individuals with mental health challenges struggle (Bruce & Aylward, 2021). In this way, self-advocacy narratives should be seen as a non-starter in that they would necessarily exclude the individuals who most need support. The fact that they have persisted and expanded over time has led Bruce and Aylward (2021) to conclude that such narratives are intended to reduce the impact of disability on universities. Herein lies another central conundrum of self-advocacy: it assumes that there is no conflict of interest between parties, when in fact an abundance of conflicts of interest may arise (Aspis, 2002). Although students are undoubtedly most interested in their wellness and academic success, university systems may have this interest alongside other concerns, such as limiting the amount of funding that is allotted towards students with mental health challenges and preventing services from becoming over-burdened. Some of our participants' stories portrayed an even more blatant conflict of interest, where they reported discriminatory interactions that suggested that some individuals want to actively keep people with mental health challenges out of university and out

of certain professions. The denial of this fraught environment conveys another way in which self-advocacy can be seen as a gear in the machinery of inequality, as it individualizes responsibility to access supports within a system that may, for various reasons, have an active interest in keeping students with mental health challenges out and away from support.

It has been suggested that existing support systems actually may be holding back students with mental health challenges, as such systems can be used to demonstrate that the university is doing *something* for students and that services are available (e.g., providing accommodation, providing free mental health services), without any further examination into whether what is being done is right, helpful, or supportive (Dolmage, 2017). As one specific example, students with mental health challenges are often provided the accommodation of extra time to write exams, even though there is little evidence to support the effectiveness and relevance of this intervention (Dolmage, 2017; Holmes & Silvestri, 2019). However, self-advocacy as it is currently employed by post-secondary institutions does not include space for demanding improved supports, but rather refers to a student's ability to navigate within and benefit from existing supports (Aspis, 2002; Bruce & Aylward, 2021). In this way, self-advocacy perpetuates inequality because it does not allow for any meaningful change to existing systems, and instead only allows for access to more or less support within existing systems which may or may not contain relevant and helpful support. Self-advocacy narratives can thus further be seen to perpetuate structural stigma by suppressing the need to address inequities via institutional policies and practices that promote them.

Self-advocacy also perpetuates inequality to the extent that it implies individuals with mental health challenges have equal power within relationships when they do not (Bruce & Aylward, 2021; Palmer, 2000). Participants described advocating for themselves to professors

and service providers who, ultimately, had the final say in whether a student received what they were asking for or were denied. In this sense, self-advocacy is troublesome because it situates upholding disability rights as a student's responsibility; they must gain access to the right supports at the right time, spend valuable time advocating, and build relationships with others to have their rights affirmed (Claiborne et al., 2011; Palmer, 2000). This onus of responsibility on students for upholding rights fails to consider that students often have the least power within universities. Thus, students may be in the worst position to effectively enforce disability rights as they can be overruled by, for example, a professor denying reasonable accommodation, or a service provider who fails to provide adequate support. Such ideas of self-advocacy imply that individual agency drives whether negotiations are successful or not when, as we demonstrated with the centrality of relationships in self-advocacy, it is in fact relationships with inherent power differentials that do so (Hibbs & Pothier, 2006).

It is also worth reflecting on the further corruption of the original use of self-advocacy that I heard within these workshops. Self-advocacy experiences described by participants in this study were in no way aligned with what is meant by self-advocacy historically or even within the current literature. Although, historically, self-advocacy was meant as an empowering term that was intended to give people with disabilities greater ownership over their lives, what was referred to in our workshops was conversations that happen predominantly within service provision, and thus further segregate and confine individuals with disabilities to a limited realm of opportunity (Bruce & Aylward, 2021). Even more recent and less radical definitions of self-advocacy differ from what was discussed by participants in the current study, as these conceptualizations still refer to the responsibility of other parties to educate and support students with disabilities in the skills necessary to successfully self-advocate (Daly-Cano et al., 2015;

Test et al., 2005). No education or support through university was described by participants in the current study, though some participants described informal connections with family and friends that supported self-advocacy. Thus, although some could argue that the development of self-advocacy skills is important and beneficial for students in university as they may require these skills later on in other settings such as employment or health settings, the lack of meaningful investment in the development of these skills speaks more to self-advocacy as a tool of institutional abandonment than as a well-thought-out strategy to support student development of essential skills. In this sense, self-advocacy may be seen within institutions as being fully individualized, as it implies full individual responsibility to both develop the complex knowledge and skills necessary for successful self-advocacy and to succeed at having one's needs met within complex and limited systems.

#### Limitations and Future Directions

There are several limitations to the current study. Although we aimed to create methods that were accessible and welcoming to participants, our methods were limited in several ways. First, in advertisements for this study and in introducing the workshop, we explicitly positioned this research as focused on exploring barriers related to self-advocacy, thus perhaps particularly drawing to our study those who have struggled in this regard. It would be interesting to see how dialogue may differ if workshops were positioned as having a more neutral focus towards self-advocacy such as, for example, "exploring experiences." It would also be interesting to explore these results quantitatively. Specifically, one could conduct a survey where students report their differing level of success in accessing different supports, and compare across supports to evaluate which qualities of supports may be helpful or harmful for self-advocacy.

Further, although we aimed to create a World Café that was accessible to participants and allowed for sharing of deep opinions, the structure and time commitment was still fairly formal. Participants had to reach out and contact me to indicate their interest, they met with me, and then committed to attend for three to six hours on two consecutive Saturdays. Although this was undoubtedly valuable in creating a safe environment for participants and acquiring depth of data, other World Cafés have used more informal methods, such as setting up in a well-trafficked area of university and allowing participants to drop-in to share their thoughts (e.g., Estacio & Karic, 2016), which may be especially helpful for getting a broader range of responses, and getting responses from those who are both more invested and well-versed in the matter of the workshops and those who are more informally interested. Given the nature of our workshops, we likely sampled more from those with greater investment in the issue at hand.

The hybrid nature of these workshops, which was pursued in accordance with participants' expressed desires, also introduced limitations to the data. The interpersonal dynamics differed between the two, where in-person participants were able to more informally discuss back and forth between each other, as well as formed greater connection amongst themselves due to the opportunity to socialize over breaks, whereas on Zoom it was typical for facilitators to be more involved in managing the flow of discussion. Further, the fact that participants were simultaneously attending on Zoom and in-person meant cross-pollination of ideas was limited, as groups could only be rotated separately among those on Zoom and among those in-person, as opposed to among the entire group of participants. Future research may more formally investigate differences in group data collection that takes place on Zoom and in-person, and explore potential methods that allow for further integration of participants attending live versus through technology.

Our methods also prioritized discussion among participants over establishing consensus. What this meant in practice was that we were left with a variety of perspectives and ideas for change with no strong sense of which were more salient or seemingly important to participants. Certain methods, such as James Lind Alliance (National Institute for Health Research [NIHR], 2020), build in more active decision-making processes focused on establishing group consensus that could be helpful for future researchers seeking to involve participants in making concrete decisions based on the discussions that take place within research.

The diversity of our sample was limited, especially as it pertains to racial and ethnic diversity and gender diversity (i.e., our sample was mostly White women). Especially given our findings from Study 1 of the potential for barriers to differentially impact individuals from various marginalized backgrounds, and for unique barriers to arise in specific populations (e.g., culturally incompetent or gender insensitive care), more exploration is needed centering specific populations. Ideally, such efforts would be led by or in close collaboration with individuals from such backgrounds, to allow participants to fully express themselves, and to ensure that researchers have an in-depth knowledge of the issues and potential challenges that may arise. Further, participants in the current study mentioned the role that specific academic departments play in shaping experiences of self-advocacy. This was not something we considered when recruiting participants, and future research may focus more explicitly on self-advocacy as it occurs in specific departments, either by designing studies which focus on specific disciplines, or more explicitly asking questions about the role of academic department in self-advocacy.

The participants in this study identified a range of systemic limitations to supports available at university. It would be interesting to discuss such limitations with others, such as counselling staff, CAL staff, professors, and administrators, to determine which limitations are

noted and what such stakeholders perceive as the barriers to and possibilities for change. Such an investigation would help identify a more complete picture of barriers in various ways. First, it would help identify which barriers students perceive that other stakeholders are not aware of, indicating where awareness needs to be raised. Second, it would help to establish which issues are shared among stakeholders including students, and help to further explore the barriers to change that exist on such issues beyond what students can perceive based on their role in the university community. Such discussions would also help to identify areas where change may be already underway. For example, I spoke with a staff member at the university about our results, and they disclosed that their organization was already working on providing a means for students to provide anonymous feedback about experiences in their organization, a change which was requested by students. Thus, such discussions among stakeholders in positions of power may help foster meaningful action both by allowing individuals to discuss what change is needed and how it may be executed, and by sharing among services and supports which changes are already ongoing. In this way, research of this nature could help address the lack of interconnectedness in supports noted by our participants.

## Chapter 4: Reflections on the Power and Pitfalls of Participatory Practices on Our Research Team

The focus of this dissertation was not solely on what knowledge was created, but also on how such knowledge was created. Specifically, I worked with a team of research assistants with lived experience of mental health challenges throughout this project. Given the central role of participatory practices in the execution of this dissertation, I now turn to a reflection on our strengths and challenges in this regard, both for the purposes of contextualizing this research, and to offer our own knowledge gained from engaging in these practices.

In June of 2022, I met individually with all four of the current research team members, three of which started in April 2021, and one of which joined in December 2021, to discuss their perceptions of our team throughout our work together. We discussed that the purpose of these conversations was to get perspectives from everyone about our work as part of my dissertation, and that members would not be named in relation to their expressed opinions. These conversations were informal, and roughly guided by a document I sent each team member which outlined by month the various tasks our team was working on in order to remind them of our different phases. We discussed our team's strengths and weaknesses, how able they felt to contribute to the team and shape the direction of our project at various points, and how they felt our team worked together. I took notes during these conversations, and sent the notes to each team member to determine whether I misconstrued any of their points, and whether there was anything they would not like included in a write-up about our team. What follows is a discussion of several key points identified through these conversations and my own reflections about both the power and the pitfalls of our team.

#### The Power of Participatory Practices

All team members, myself included identified strengths of our team that were uniquely valuable and shaped both the research project and our engagement with the research project in a positive way.

#### Commitment and Accountability

I noted that the involvement of team members with lived experience had a positive impact on my commitment and accountability. The vital role of fostering a higher standard of accountability has been noted as one of the core benefits of utilizing participatory practices (Lake & Wendland, 2018; McCartan et al., 2012; Rempfer & Knott, 2002). As a graduate student, I have often experienced the disconnect between the big ideas I want to pursue, and the stretched time and responsibility I have to commit to various projects. The way academia is structured often prioritizes the value of one's work in terms of scholarly achievements, such as publishing academic papers and presenting at conferences, as opposed to the real-world impact of the work one is doing. In the past, I have often had aims to make use of my research for the betterment of the community, but ended up sidelining these as more academically-related opportunities arose. Looking back, this was for several reasons, including wanting to pursue opportunities that relate to career advancement, but also feeling uncertain about the value of my research for the community.

Being on a team with individuals with lived experience altered this drastically. I took seriously at the outset that if I was going to be asking for a large investment of time from individuals with lived experience, I would not want members to feel that this was an exploitative relationship where I was using their knowledge to enrich my own career without providing anything in return. Although this remains a core component of accountability, over time my

accountability evolved beyond solely doing what was right for the research to doing what was right by the people involved in this research. What I mean by this is that, by prioritizing lived experience in this research, our team developed caring relationships with each other that involved hearing about each others' experiences of maltreatment and structural injustice within the university system. By way of these relationships, commitment and accountability to the project was fostered as the need for change was not just identified by participants with which I had fleeting interaction, but by those to whom I had ongoing relationships and commitments. The power of participatory practices here was that it deepened my own understanding of and investment in the issues I was researching, especially those with which I had more limited lived experience, which in turn engendered a greater ongoing commitment.

Accountability and commitment were also fostered by how the research process itself was impacted by working with individuals with lived experience. In past projects, I had only my own theorizing and that of other scholars to draw upon for solutions or interventions. This left me feeling uncertain about whether I, as someone removed from the community, had the ability to truly understand what changes may be helpful, and often resulted in vague recommendations and ideas for change, as I was not in a position to fully understand the problem or the various possibilities for change. Having a research team of individuals with lived experience of the problem at hand thus fostered my own accountability and commitment by way of facilitating more in depth understanding of the community issues at hand, and creating a positive role to play in advocating for change.

Similarly, although my strengths do not lie in brainstorming and executing creative solutions to help translate knowledge and create positive impact based on research, team members with lived experience were often more well-versed in this area. In some cases, team

members had experience specific to communicating with, for example, university administration or the broader campus community, and others had experience in the use of social media and forming interprofessional relationships. These specific skills were undoubtedly valuable. Furthermore, the team was also valuable insofar as they seemed less inhibited or bound by institutional rules and etiquette. When we came across the name of a person who may be helpful or had an idea for how to get the word out about our project, the team attitude was consistently, "Why not just try it and see what happens?" where my own attitude historically has at times may have been that I did not feel I had the expertise or the power to talk to certain individuals. Thus, accountability and commitment were fostered by team-based innovative thinking and approaches that made ongoing accountability more responsible and feasible.

#### Enjoyment

Another key benefit of utilizing participatory practices was the enjoyment of the research process fostered within this environment. Although this may seem like a "soft" or somewhat irrelevant point, enjoyment was central to our process. Indeed, Reid and colleagues (2006) similarly discussed that one of their most salient findings within team reflections among their participatory research group was how much their team participants enjoyed the connection and solidarity experienced in their team. In my individual discussions with team members, every member agreed: we enjoyed working on this project, and often even had fun. One team member stated that this was essential to their participation, as so much of what we were working on involved very serious topics that had greatly impacted them and people they loved. This member was initially concerned that working on such issues may cause them distress, but instead felt that in practice the passion and humor brought by team members made this a rewarding experience.

As the leader of this project, if I was getting disheartened, the team's excitement for the project

and belief in the value of what we were doing bolstered me. This has been affirmed elsewhere, as van der Meulen (2011) notes the key role participatory projects can play in combating isolation and alienation that is common among graduate students. In the face of complex structural issues and limited power, this work can be disheartening, but in an environment of solidarity, we found that support and encouragement from each other kept us engaged and involved in the project, at times if only because we enjoyed working with each other.

#### Team Diversity

Team members similarly agreed that the diversity of our team was an asset. This diversity was referred to in terms of mental health concerns, academic background, and intersectionality including racial minority status, sexual minority status, and age. As has been noted elsewhere, such diversity allowed us to be mindful of weaknesses in our research by having diverse representation from the community of interest (Muhammad et al., 2015). This diversity was valued amongst our team not only for how it influenced the quality of the research, but also how it influenced our research process. Those team members who began with the team in April 2021 all discussed a feeling of excitement at the composition of our team for the opportunity it gave them personally to expand their understanding about others' experiences. Team members also expressed that they felt our team embraced diversity by noting that conflicting opinions and disagreement were common, and were able to be discussed respectfully and with mutual appreciation for each other. Openness of team members was described as central to this process, as knowing about team members' experiences and identities fostered empathy and interest in each others' perspectives. The importance of this openness extended to me in my leadership role, as one team member also expressed that, although they were initially hesitant that they would not be able to express their true opinions to me due to my position of power, the way I discussed my

role and positionality in early meetings facilitated their trust. Thus, it was clear that the diversity of our team was an asset not only simply due to having people of diverse lived experiences together, but by the intentional work we did as a team to foster an environment where the varied experiences of participants were encouraged to be shared and valued.

#### Conferring Opportunity and Importance

Others have highlighted the role that participatory practices play in improving the power and opportunities of individuals from marginalized groups, both by having power to influence the research process (Lake & Wendland, 2018; Rempfer & Knott, 2002) and through a range of tangible benefits such as resume enhancement, preparation for the labour market, and involvement in academic publications or conference travel (McCartan et al., 2012; Muhammad et al., 2015). This itself is seen as a form of action of participatory practices via building capacity of those with lived experience in terms of tangible skills, but also through fostering collective action and political mobilization (Mosher, Anucha, Appiah, & Levesque, 2014). At the outset, I did not understand how much of an impact allowing research assistants this one research opportunity could have. Beyond the tangible benefits mentioned above, I have been a reference for team members for volunteer positions, housing, and employment in the community, and have been a point of connection to other researchers and research projects. Team members' role on this project has lended them credibility within the research role, and during this project several team members have taken on additional research and professional roles in other areas of interest that may or may not be directly connected to their lived experience. The notion that "opportunity begets opportunity" was borne out here, and thus participatory practices can play an important role in allowing individuals with lived experience an initial "foot in the door" that they can then use to acquire further opportunity.

Team members also noted the value of this opportunity to foster their engagement in academics and convey their own importance. One team member felt that their involvement in this project increased their engagement in university overall, and served to boost their confidence in their own academic abilities. Several noted that the valuing of lived experience specifically within this research team conveyed a sense of importance of their experience. In this way, although the position of power researchers hold is often a tension within participatory practices, such researchers are uniquely positioned to use their power to send a message of validity and importance to marginalized groups. This had the potential to transform experience, as one team member who said they had often felt their lived experience was something that consistently held them back, now saw that their experience uniquely positions them to make valuable contributions to knowledge. Thus, the impact of sharing power among those with lived experience had the potential to influence how participants saw their own belonging and value within academic settings.

#### Rewards of Power

Among discussions with team members, there was a clear message that the benefits of participatory practices were most fully realized when team members had the most power and influence over the process. Study 1 of this dissertation was mostly designed by the time team members became involved, and thus team members had a more consultative, editorial role in this study. In Study 2, on the other hand, our team decided together what we wanted to focus on and on nearly every aspect the design and implementation. In line with this, all the team members involved in both Study 1 and Study 2 discussed that the design and implementation of Study 2 was a highlight. Though members discussed challenges and fears associated with developing and facilitating workshops, they discussed that it was rewarding to have ownership and to push

themselves to take more of a leadership role. This was also described as the phase of research where the most teamwork was needed, as everyone felt they had the responsibility to contribute ideas to the development of the project, and that they had a well-defined role as a facilitator within the workshops. In my view, this was also the phase of research that most clearly allowed the benefits of lived experience involvement to be realized, as I felt our team was asking fundamentally different questions than would be asked if individuals with lived experience were not involved, capitalizing on team members' unique knowledge and insights (Jones et al., 2021; McCartan et al., 2012; Muhammad et al., 2015). Team members discussed that this was when they felt most connected to the project, most excited about the direction of the research, and most confident in their own value as team members. This re-affirms the importance of researchers yielding power and letting those with lived experience drive the research process in order for the full benefits of participatory practices to be realized (Bergold & Thomas, 2012).

#### Allowing for Mental Health Struggles In Practice

Given that lived experience of mental health challenges was what was prioritized in this team, we also made special considerations to ensure that such lived experience was truly welcome in our team (Jones et al., 2021). In practice, this meant ensuring that meetings were scheduled in times that did not conflict with appointments or other supports related to participants' mental health, that our team was adaptable to members who were intermittently absent due to life or mental health circumstances, and that we were flexible in assigning and reassigning tasks. Here, our team discussed openly what individuals were able to take on for work at different times, and if there were certain tasks where they required adaptation or that they were not able to do. This balance was not always straightforward. For example, although everyone on our team had different personal circumstances that influenced our work on this project, we coped

differently: some found continuing to regularly attend meetings a source of comfort and purpose during challenging times, but for others it was necessary to take short periods of time away from the project. In practice, this meant that those who found ongoing engagement helpful were the ones who had more say in the day-to-day decisions and direction of the project than those who needed time away, as they were present at more meetings, and thus contributed to more decision-making processes. Our team members valued their contributions to important decisions likely in part because team members rarely missed more than one meeting at a time. One could see the risk in this is that those individuals who struggle more, or whose struggles impact them in a way that makes ongoing participation challenging or impossible, become more marginalized in the decision-making process. How to utilize participatory practices in such a way that promotes meaningful engagement specifically of individuals with diverse mental health challenges must be continually considered both in light of ensuring team members are honouring their own needs, while at the same time not being excluded from engagement.

#### **Enacting Transformative Environments**

Perhaps the most important benefit of participatory practices is the extent to which it allowed us to create micro-environments aligned with our desires and goals for larger structures. Early on, our team discussed that we needed to operate in a way that was fundamentally different to the structures we were researching. We needed to be flexible and responsive to each others' needs, to have space for who we all were as individuals, to be non-judgmental, and to be supportive of each others' growth. In this way, it felt that we had some power in *already doing* amongst ourselves what we wished we could do at the university level. For me, it felt like an opportunity to put into practice on a small level some of the larger changes I have proposed in this dissertation. I got to experience firsthand both the value and challenges associated with, for

example, attending to individual needs for work via relationships and ongoing discussion with team members, as opposed to the more rigid accommodation systems where a person's needs were identified for me by a diagnostic classification and set list of accommodations. The same is true for utilizing diverse hiring practices that prioritize lived experience, and, in some cases, individuals having had a *lack* of opportunity to learn certain skills, as opposed to awarding those positions based on work experience and grade point average. Going forward in my own work and leadership, this gives me a more in-depth perspective on what challenges may arise as certain solutions are pursued, and the value of the types of changes I propose. In essence, I feel my imagination for what is possible is expanded by virtue of engaging with this team.

## The Pitfalls of Our Participatory Practices

My discussions with team members and my own reflections also highlighted several areas of challenge within our team.

## Creating or Maintaining Hierarchies

Participatory practices aim to equalize power and disrupt hierarchies. However, there were several ways in which hierarchies were created or maintained within our project. The role of hierarchy was demonstrated at the outset when I was in the process of hiring for our research team. Positions on research teams are highly sought after among undergraduate students, not solely due to their investment in the issues at hand but also because such experiences are often required for applying to graduate school, but are often challenging to acquire. All of this is to say, I received a large number of applications for positions on this research team. In this way, right at the start of the project I was put in a powerful, evaluative position assigning privilege to who gets to participate and who does not (Bergold & Thomas, 2012).

This was further complicated by my desire to hire individuals with lived experience. When I spoke to one individual who applied to be on our team initially but was not hired, they expressed that it felt like they had to market their suffering in order to be seen as competitive. Further, they expressed a sense of inferiority that their own mental health concerns were not "serious enough" compared to other applicants to receive a position on the team. It is indeed true that I aimed specifically to have a team comprised of individuals with mental health challenges that were less well-represented (i.e., not anxiety and depression), and aimed to have a team who were multiply involved in different services and who discussed a range of structural barriers and impacts of their mental health challenges to ensure that the team was comprised of individuals who had experience with the issues I intended to study (Jones et al., 2021). However, in practice the hiring dynamic was complicated, as I was in a position of power asking people to disclose their personal experiences without knowing much about me, and then in a further power position of evaluating this lived experience. All of this reminds me of dynamics in other systems, such as CAL and counselling, where opportunity is determined via assessment by a powerful professional. This process may have excluded those who were not comfortable disclosing, or who may have struggled to describe their experience in terms that I could identify and understand. So long as opportunities are limited, hiring practices will always introduce issues of power and comparison of individuals. However, I discussed with the member who was not initially hired what may have been done to improve the hiring process. They made suggestions such as allowing for video submissions of lived experience summaries, and having meetings with applicants to discuss their lived experience so that disclosure can happen more relationally. Future research and practice should work to establish guidelines for hiring practices that are

respectful of applicants and power dynamics, while at the same time supporting goals of hiring teams with diverse lived experiences.

There were also several ways in which hierarchies were created or maintained within our team. As Muhammad and colleagues (2015) noted, power differentials based on characteristics such as gender, racial/ethnic background, and socioeconomic inequalities can be re-created within participatory research teams. A racial minority member of our team confirmed this, discussing how, especially early in the project, they were highly conscious of what they should or should not say as a racialized person in an otherwise White group, and was concerned about the power that White people hold to create negative consequences for racialized people. Thus, this member discussed experiencing distress and censoring themselves early in the project. For this member, this dissipated with time due to how team members engaged in listening and discussion related to racialized student issues. However, this member felt that throughout the project, they were not experiencing the same level of comfort in the group as other members, reinforcing the ongoing work needed on participatory teams to challenge existing social hierarchies.

Similarly, marginalization was created in our team due to team members having different levels of socialization to the research environment. As has been noted elsewhere, researchers occupy power positions not only by having higher education levels or more titles, but also by working in an environment that is familiar to them (McCartan et al., 2012; Muhammad et al., 2015). Reflecting back, I found not only that the research environment was familiar to me, but that it was differentially familiar to different members of our team. Although no members of the initial team had previous experience working in a research environment, members came in with differential experiences with formal employment, advocacy, and education. Some had worked in

mainly highly hierarchical jobs where they had little power and input, or been in classes that were largely lecture-based, whereas others had held more power both within employment and their education to have their voice heard, and especially to have their voice heard among those in positions of power. In our team meetings, members also discussed differences between them in terms of social class, racialization, age, and the norms of their upbringing regarding relationship to authority. For example, one team member noted that they struggled throughout to understand the social rules of the research team regarding what they could and could not share personally, and was initially confused at how the research process worked. Although several of our early team meetings were spent discussing how we would work together as a team, what the norms of our work would be, and reflecting on how the team process was working for different members, it is clear that these group discussions were not sufficient for all members. Some adapted quickly and felt comfortable in our team environment, whereas others were less certain of their role on and contributions to the team. In this way, those who socialized less easily to the research environment were marginalized to the extent that they felt unclear or uncomfortable navigating.

Upon reflection, I unwittingly created hierarchies by assigning different opportunities to team members. Specifically, one team member identified early that they were working towards the requirements they needed to apply to graduate programs in clinical psychology. Knowing this, I offered to co-supervise an independent study project that could act as an Honours equivalent for the team member. At the time, I was focused on my responsibility to support the goals of research team members by providing opportunities where possible (McCartan et al., 2012; Muhammad et al., 2015), and my ability to offer an opportunity that was directly relevant that the team member may not otherwise have been able to access. Upon discussion with other team members, however, this differential opportunity between members created a hierarchy,

where other members felt jealous or that they were marginalized in their involvement in the project in comparison to the member who was completing their own project. Similarly, the team member who had the opportunity did feel that their independent project led them to be more engaged and committed to the project than other members. Thus, providing opportunities to team members must be balanced with the hierarchies that may be created by providing such opportunities. Though I do not necessarily think that I should not have given such an opportunity, it certainly would have been useful to discuss more in the team as a whole the rationale for the team member pursuing an independent project, and may have also been helpful to have the team to be more involved and knowledgeable about that portion of the project. Further, although my personal capacity to provide opportunities was limited, teams may focus on being built at the outset to be able to provide expanded opportunities to team members by, for example, having multiple individuals in leadership roles who can facilitate individual opportunities, or fostering connections with other researchers or community organizations who can provide opportunities to team members.

One of the most complex challenges to the hierarchy of our research team was the social relationships that were developed as the team progressed. In my reflections with individual team members, everyone discussed the development of differential social relationships among the research team. As we continued to work together, some team members developed social relationships where they would spend time or communicate with each other outside of solely the research meetings, and others did not. This led to different perceptions of the team dynamic, where some felt more inclusion and solidarity with the team, and others felt more excluded. This dynamic extended over time, where as certain team members developed closer relationships, others felt more isolated and excluded, and thus less comfortable sharing socially within research

team meetings. Reflecting back, I have also wondered about the degree to which certain members' suggestions were listened to and incorporated over others due to differential social relationships, thus marginalizing those who were less socially involved in decision-making processes. This is a complex area and one which is, to my knowledge, under-theorized. In a type of research that values positive relationships between team members as necessary for trust and productive participation, what is the role of the lead researcher in navigating or facilitating when differential relationships between team members arise? Researchers cannot and should not have control over how team members spend their social time, and members will connect differently due to a range of factors. Thus, the role of the researcher here is to be aware of and open to discussion among the team, both individually and in a group, of how social dynamics may be influencing the team's work, both in terms of how work is done concretely and how team members feel they belong on the team, and to discuss with members how to foster a positive and inclusive environment. Such discussions must be re-visited frequently as team dynamics shift over time. Indeed, in the individual reflections held for this write-up, the influence of social relationships was a focus of conversation among several different members. The opportunity to discuss individually the state of team dynamics and the role each member played in the creation of dynamics led to changes at our next team meeting that created a positive shift in the work environment.

## Conflict Between Efficiency and Process

Another tension experienced by our group over time was finding a balance between ensuring adequate time to connect, to share diverse viewpoints, and efficiency. In team reflections, several members reflected that at the beginning of our work, they appreciated having time to get to know each other and connect. However, as our work progressed, several team

members reflected that they at times became frustrated with getting distracted from goals in meetings to discuss team members' personal situations, or frustration that seemingly small decisions felt painstaking when each member expressed complex opinions. These differing views on the importance of efficiency led to tension in the team at several points during our work together, where some members became frustrated with the pace and attempted to quickly discuss issues and move on, whereas others felt left behind or that their needs were not being met when such efficiency was prioritized.

I do not believe there is one "correct" answer of how to balance efficiency with research tasks, or that the answer is the same throughout a project. Although participatory practices do necessitate adequate time to engage and hear from team members, our team faced real time constraints that at times necessitated quick decisions in order for the project to be successfully realized. Further, part of ongoing engagement for some team members was the feeling that decisions were being made and the project was moving forward, as opposed to stagnating or becoming overly focused on smaller details. Here, in the absence of a clear solution that satisfies all team members, transparency is paramount. Discussions among the team that focus specifically on the issue of efficiency in terms of how it operates as a value on the team, when it needs to be prioritized, and when it does not would help create group norms and expectations for how work is to be pursued at different parts of the project, so team members can have the same expectations for why the team is operating as it is at different times. One team member also suggested that meetings that had fewer team members present also facilitated a better balance between efficiency and group processes as opposed to meetings where the whole team was present, as such meetings allowed more time for connection with each other and allowed more space for each member to have input leading to a decision.

## Slippage in Participatory Practices

Upon reflection, I noticed my own slippage in engaging in participatory practices as a team leader, both over time and specifically in situations where time constraints were present. It was not until I stopped to reflect on our work as a team that I realized that I had lapsed in several efforts that were important for successful participatory practices as the project evolved. Specifically, at the outset of the project I ensured I had more individual meetings with team members to discuss how their work was going and any feedback they had for me or the team in general. Early on, we also had team meetings specifically devoted to discussing our process as a team and discussing any issues that were arising. These meetings were helpful means to connect with individual members and re-affirm the norms of our group. When examining why I failed to continue in these efforts, which were positive for the team as a whole, I thought about the degree to which I assumed that such efforts were those that were used for initial engagement, but that as the group evolved I (mostly unconsciously) assumed that the relationships built among myself and the team members meant that team members would reach out to me or raise in a meeting if any issues were arising. After meeting with team members for their reflections, my view now is that some members may have been holding back their opinions from the group, whereas others were operating moreso in alignment with how I was in terms of assuming the team was working properly and not noticing issues because there was not embedded time in our process to reflect on the team. Through this, I now understand the importance of continually having time for individual and team reflection not just about what we are doing, but about how our work is going. This is a key process not only for creating space to address issues, but also to ensure that team members, myself included, are taking the time to attend to our process and any challenges that are arising, as opposed to being solely focused on the content of our work.

Similarly, our team fell into fairly well-defined "team roles" within our work, which limited member potential for learning and leadership. It has been noted that it is important to share knowledge via "up, down, and peer mentorship," where different members of the team can learn from each other throughout the research process (Muhammad et al., 2015). Although this occurred in terms of learning about each other's perspectives, over time our team fell into the habit of sharing less knowledge about concrete tasks among each other. Specifically, we defaulted to assuming team members would do the tasks aligned with their identified strengths, as opposed to working together to learn new tasks. At times, this was due to time constraints, where tasks had to be done quickly and thus it felt logical to the team to assign it to someone who already had the expertise. At others, however, tasks were assigned this way not out of necessity but out of habit. Though most were happy sharing general tasks amongst each other, and having more specialized tasks assigned to those who already had the relevant skills (e.g., assessing language use for accessibility and sensitivity, graphic design), one member expressed that they wanted more opportunity to learn skills outside of their areas of knowledge by being partnered with those who are more knowledgeable and working on pieces of the project together. Thus, for our team we fell into the habit of working as a team in a particular way and, in the absence of time to reflect on how this way of working was or was not aligned with team members' goals, operated in such a way that limited the learning experiences of members.

I also noted that my own transparency slipped over time, and when time pressures were present. The role of academic researcher transparency within participatory practices about required outputs, timelines, and responsibilities to different groups is central (Bergold & Thomas, 2012; Reason et al., 2011). Although I was careful to share this information with team members early on (e.g., discussing timelines associated with ethics review, survey development),

I was less consciously engaged in this at various points in the work. This especially occurred in phases where the goals and timelines of our work were less well-defined. At the outset of this project, I had general ideas of the two studies that would be involved, roughly when they should be completed, and the steps needed for our team to undertake to reach these goals. As we completed these two studies, our team went through a more amorphous phase where it was not clear to anyone, including me, what our next task would be as a team. At this time, I was also very focused on writing this dissertation and meeting the timelines associated, which was largely an individual effort that at times distracted me from larger team goals. These factors combined to negatively impact my transparency: both transparency about entering a new phase of our work that was less well-defined, and regarding the strain I was feeling associated with the timelines and workload of writing a dissertation. Instead of communicating this, I found myself scrambling to quickly come up with some sort of task for us to work on as a team to maintain team engagement and contribution. These tasks ended up being confusing and feeling irrelevant to team members, when, upon reflection, it would have been more beneficial to the team to be honest about the nature of the phase of work we were in and my own limitations. Such communication may have resulted in the team making different decisions such as taking a hiatus, or focusing on our relationships with each other and process for several weeks while we developed what our next phase of work would look like.

My own participatory practices also slipped in association with tight timelines. The best example of this is the hiring and training of additional research assistants to assist in running workshops for Study 2. Although Study 2 itself was designed thoughtfully and with much discussion among the core team, several constraints arose suddenly that led to immense time pressures to hire and train additional facilitators. These constraints included things such as

addressing last-minute committee feedback on the design and analysis of Study 2, managing a family emergency, wrapping up the end of the fall term, and adapting Study 2 due to the onset of the Omicron wave of COVID-19. Additionally, our team decided that, in order to maximize participant engagement, our workshops must take place within the first month of the new term before students become overwhelmed. I coped with these time constraints by temporarily taking a more traditional leadership role in quickly selecting individuals who I thought would be interested and have the relevant lived experience to help facilitate workshops, and taking more of a leadership role in training facilitators, making PowerPoints of facilitating tips and monitoring role plays as opposed to the more discussion-based way in which our team typically operated. All of the original team members identified that the integration of these new facilitators was one of the more challenging times for our team, as the team as a whole had not built trust with each other, and there was little time allotted to do so. These slippages and what led to them feel important to highlight, then, as areas of particular attention for researchers making use of participatory practices to be especially aware of and reflective on in their own processes.

#### Leadership Challenges

Finally, it became increasingly clear to me as a leader that such a role requires personal reflection and growth. As has been noted throughout this section, reflection and open conversation among the team are often enough to course correct issues that will inevitably arise when working in this way. Such efforts need to be set as the norm by the leader, which means that the leader themselves must be attuned to their own barriers to engaging in this way. As mentioned already, for me, such barriers include my own stress as well as my response to being under time constraints, both of which I cope with by working independently to ensure tasks are completed efficiently. Among discussions with the team, I also learned that members at times

felt tasks were unequally delegated, or that they wanted to do more work on the project than I was giving them. As I imagine may be common among individuals engaged in participatory practices, I often felt so indebted to team members and grateful for their time that I felt guilty assigning too many tasks and cautious of over-burdening them with work. In practice, this meant that team members who were more assertive and proactively volunteered for tasks were assigned more, and that I took on tasks myself that I now understand other team members would have liked the opportunity to try. Thus, awareness of one's own leadership strengths and areas of struggle, and actively working on areas of struggle, are important to the success of participatory efforts.

In discussions with team members, several also emphasized that part of being equal as team members is allowing myself as a member to tend to my own needs. Throughout this project, I made several personal decisions that impacted our work, such as moving provinces for personal reasons and shifting our team to Zoom, when I knew all team members (myself included) preferred to meet and work together in person. At times, I felt when reading the literature on participatory practices that engagement in such practices required superhuman skill and self-sacrifice, and thus felt intimidated or as though I had failed when I attempted to balance the work of this team with other life constraints. Discussions with team members left me with the opposite feeling, that team members desired to work in a way where everyone's needs were honoured, including leadership. This, of course, must be done thoughtfully by leaders so as not to result in exploitative practices or a flippant attitude towards putting one's own goals and outcomes ahead of the team's. However, I admit that discussions with team members that portrayed an acceptance of my own humanity and limitations as just another part of the team came as a relief. Having the space to fall short and to be human in the presence of striving to

engage, to relate, to share power, and to act for change feels essential to the sustainability of these practices. I discuss this as a pitfall as, I believe, if researchers attempting participatory practices put unrealistic expectations on themselves, they may become paralyzed or give up on the pursuit of these practices. As this team affirmed, the purpose of these teams is to cultivate trusting and open relationships that re-envision one-size fits all expectations of how to do it "right" with complex and thoughtful decisions made that consider the multiple priorities and responsibilities that each member holds.

In sum, this experience allowed our team to see the power of participatory practices, as well as experience many imperfections and shortcomings. When challenges arose, reflection and discussion among the team was a key component of moving forward. Such reflection works best when grounded in sustainable work processes that value the process of how work is done as much as the end results. Reflecting back, I also wonder about the extent to which some leadership challenges could be circumvented by having multiple leaders on a project, who may be better positioned to provide a "check" to each other if they notice one is slipping in their practices, and expand the capacity of a team to provide opportunities to its members and spend one-on-one time with members to facilitate reflection and skill development. Having worked as a leader of a team such as this, it seems to me that practical experience is important in this area, and, although reading literature of best practices and recommendations is helpful, attempting participatory practices, learning through the process, which involves making mistakes and falling short, and trying again is essential for developing the skills necessary to successfully engage in participatory practices. In this way, participatory practices may be not a series of boxes to check or concrete processes to engage in, but rather a way of being and working that involves attention,

flexibility, and evolution as a group strives towards equality, connectedness, and the creation of projects that meaningfully incorporate community perspectives.

# Chapter 5: Implications of Findings for Anti-Stigma Agendas and Proposing a New Way Forward

Reflecting on "Psy" Dominance, the Services Agenda, the Rights Agenda, and Structural Stigma

At the outset of this dissertation, I outlined the impacts of "psy" dominance, and outlined several different dimensions of stigma and their associated anti-stigma approaches, focusing on structural stigma as a useful framework for acquiring a greater understanding of how and why stigma operates as it does. I will now reflect on the implications of our findings for these concepts and approaches, specifically commenting on the limitations of both the services agenda and the rights agenda, and summarizing overarching findings related to structural stigma.

To refresh, the services anti-stigma agenda focuses on reducing the stigma of mental health challenges to increase help-seeking behavior among those experiencing distress (Corrigan & Al-Khouja, 2018). Deeply rooted in traditions of "psy" dominance, this agenda largely ignores the structural context of distress, and instead conceptualizes distress as situated within the individual, and situates barriers to seeking services within the individual. Importantly, this agenda can at times occur in the absence of any meaningful effort to address the lack of appropriate and accessible services (Tyler & Slater, 2018). Unsurprisingly, the findings of this dissertation strongly refute the aims of this agenda. In both Study 1 and Study 2, we found an abundance of barriers related to help-seeking that had nothing to do with how an individual *feels* about seeking help. Many participants in both our studies described a strong desire for support, but found support services inaccessible, over-burdened, ineffective, not applicable to student needs, and challenging to navigate. On top of this, we found evidence that, when some participants reached out for help, they were met with messaging from service providers and

professors that reinforced the very stigma that the act of "just reaching out" is meant to dispel: that students who claim mental health challenges are exaggerating (or lying), that they are incapable, and that they are not worthy of support. This is not to say that the services agenda is inherently ineffective; if the evidence demonstrated underuse of high quality services, then a focus on increasing use of services could be an area of focus. Since this is not the case, this agenda appears to maintain the status quo by ignoring structural aspects to both distress and the process of help-seeking, thus perpetuating inequitable structures (Tyler & Slater, 2018).

The services agenda further falls short in that it promotes a narrow view of what contributes to well-being aligned with psychocentrism. Basically, this agenda individualizes suffering and suggests that one must receive treatment to learn about personal interventions to improve wellness (Corrigan & Al-Khouja, 2018). Here, our study contributes by offering a rich picture of how, for university students with mental health challenges, their wellness is inextricably tied to their academic experience. Given that academics was participants' main pursuit, it is logical that participants spoke not only of mental health and health service providers contributing to their wellness, but also of professors, of academic advisors, and of peers. Here, we saw that wellness was determined in part by the opportunities one has within the realm to which they are currently dedicated. In this way, wellness was fostered or harmed by the extent to which participants were able to take courses that were of interest to them, the extent to which they felt they had some control over and understanding of their educational experience, and the extent to which they were able to have rewarding experiences, whether it be academic or interpersonal success, within these domains. Thus, the services agenda sells short the role that equitable access to meaningful life opportunities plays in cultivating wellness.

As this project progressed, I began to think of several other ways the services agenda may be deeply damaging. Reflecting both on the results of this study and my own experience of working as a student clinician in both community youth mental health as well at the University of Victoria's Counselling Centre, I wondered to what extent the services agenda may be damaging to the therapeutic encounters that take place within these settings. Both from participants in this study and from former clients, I have at times heard a fervent insistence that just getting in to see a trained professional would result in radical life change, followed by frustration and disengagement when this does not turn out to be the case. At times as a student clinician I was frustrated by this, as I felt clients had unreasonable expectations that therapy contained magic that was going to make right years of fraught relationships, of internalized devaluation, and of a range of other deeply entrenched life situations and ways of being. Instead, what I had to offer was the relationship I formed with them, which took time, a range of options for new habits that often involved painstaking effort before any real change was noticed, and a space to explore the things about life situations that cannot be changed or controlled. Through my work on this dissertation, I have come to realize that this unrealistic perception of what professional services can offer is influenced by, and potentially originates from, the ongoing drone of the services agenda that ends its narrative at "just reach out." In this way, the services agenda and promotion of the "psy" disciplines as the path to wellness can be damaging both to clients and "psy" professionals alike insofar as it promotes unrealistic expectations of what these services do and the simplicity with which this is accomplished. This likely contributes to the frustrations expressed especially by participants in Study 2 that, even when help was received, it was inappropriate or felt irrelevant to their situation. Going forward, it is logical for the services

agenda to paint a more realistic picture of the complexities that come *after* reaching out, as opposed to over-simplifying a complex and challenging process.

The dominance of the services agenda may also negate other forms of redress that individuals could pursue. For example, our research team was fascinated by the finding that, especially in Study 2, participants discussed at length how much they believed in peer support and desired greater access to peer support. This was curious to us, as our team was aware of several peer support organizations on campus doing good work, and also aware that these organizations were so under-utilized that, in some cases, they were losing volunteers because these volunteers were frustrated that no one was coming in to utilize these supports. Although this disconnect between expressed desire for peer support services and actual utilization of peer support services warrants further exploration, our team informally discussed our own perceptions and potential barriers to using peer support. We discussed fears of peer support including potential judgmentalness of peers, lack of trustworthiness of peer services, and lack of adequate qualification of peers to adequately support individuals who are struggling. All of this clearly reflects messaging of "psy" dominance and the services agenda, where professional help is required, and any other help that is not highly educated and registered is, at best, ineffective, and at worst, potentially dangerous (Walker et al., 2017). Thus, one can see that another consequence of, broadly, "psy" dominance, and more specifically the services agenda is the potential rejection of forms of remedy or support outside of these "psy"-based institutions. In this way, the services agenda may contribute to the problem of over-burdened services by promoting the path to wellness through professional services, rendering invisible other potentially more accessible community-based supports.

Shifting to an assessment of the rights agenda, the results of this dissertation point to limitations of this approach, as well. The rights agenda purportedly focuses on institutional forms of discrimination, and challenges laws, policies, and practices that deprive individuals with mental health challenges of opportunities in areas such as housing, education, and work (Corrigan & Al-Khouja, 2018). This agenda clearly aligns more closely with the aims of this dissertation than the services agenda, as it situates approaches to ameliorating distress not only, and not mostly, within the individual, but within the structures around them. Thus, whereas the services agenda is aligned moreso with public and internalized conceptualizations of stigma, the rights agenda is aligned with structural conceptualizations of stigma. There is much to value in this approach, and in the utility of changing laws, policies, and practices as a mechanism of reducing stigma as opposed to targeting public attitude change. Indeed, participants spoke at length about the institutional structures, procedures, and policies that were harmful, such as unclear or unavailable information about options for supports, getting stuck in referral loops, and presumptions of fraud within disability services. Thus, the need for countering the structural stigma that exists within these policies and practices is clear. However, several of the issues identified in this dissertation reflected problems of implementation and unintended consequences of potentially well-intentioned laws and policies, highlighting potential shortcomings in the rights agenda.

First, it appeared to me from the results of this dissertation that the codifying of disability rights, as they are currently implemented, has the potential to contribute to adversarial relationships and exclusionary structures. Participants in both studies talked about being treated by others (e.g., CAL staff, professors), as potentially deceitful individuals attempting to perpetrate fraud when attempting to access disability rights such as accommodations. The burden

of proof was on students to collect information "proving" their disability, and even after acquiring proof some participants still reported being treated, by professors in particular, as seeking unfair advantage. The disability rights that are on offer through the university, then, seem to be perceived by staff as limited and at high risk of being unfairly seized by mentally well imposters. In this way, the rights agenda as it is exercised in relation to disability accommodations can also perpetuate "psy" dominance insofar as it requires the involvement of professional arbitration to determine who holds rights and who does not. Thus, although ostensibly a system set up to honour disability rights in terms of equal access to education, disability rights as they are implemented put students with disabilities in a precarious position where they may be exposed to a range of degrading processes and interactions for a chance at accessing rightful supports.

Rights as they are currently implemented can also focus on outcome over process.

Dolmage (2017) provides a very literal illustration of this, describing an image of a building that was required to be made accessible for a wheelchair user, describing it thusly:

The image shows a view of the concrete ramp from the sidewalk in front of a small, redbrick, semidetached house. The ramp has 10 levels—it runs diagonally from side to side 10 times. The entire ramp is enclosed on both sides by heavy gauge steel railings. Imagine: How long does it take to get up or down this ramp? How does the ramp stigmatize the family, as every other home has a small grass lawn in front, but this house has thousands of kilograms of steel and concrete? (p. 76)

The argument here is that rights, as they are currently implemented, require universities to demonstrate that they are doing *something* to support students with mental health challenges (i.e., demonstrate an outcome), without evaluating whether what they are doing is truly addressing the

needs of the student, or, indeed, whether such efforts are causing unintentional harms. As mentioned earlier, a clear example of this is the ubiquitous use of extended time on tests for students with mental health challenges, without supporting evidence for the efficacy of this strategy (Dolmage, 2017; Holmes & Silvestri, 2019). Indeed, Moeller (2018) suggests that accommodations are first and foremost expedient as opposed to focused on inclusivity. We heard similar stories among our team and from our participants where, for example, students had permission to write exams with extended time in a separate room from their classmates, but had experiences where the room was changed at the last minute, thus making them late and distressed during their exam, where various features of the exam room were more distracting than if they had written the exam in their classroom, and where they felt stigmatized and isolated from other students by being noticeably separated from fellow students in order to receive their accommodations. Further, several discussed experiences of being treated with greater skepticism by CAL exam administrators than they would be had they written in a regular classroom. Thus, although a noble goal to ensure equitable access to education for students with mental health challenges, the implementation of disability rights in the form of accommodations suggests the potential for ineffectiveness, burdensomeness, and stigmatization.

Finally, the rights agenda is limited insofar as it fails to address various complexities within the process of seeking rights. For example, although our participants identified as students with mental health challenges, many described barriers to actually accessing disability-related rights including a lack of knowledge that they qualified for such support, inability to access necessary services (e.g., diagnostic services), and wait times and delays to being approved for disability support. Centrally, our participants described that much of the burden of claiming rights in practice fell to the student themselves: they had to have the knowledge of services, the

time and resources to access them, and the skills to communicate their situation to the appropriate people at the appropriate time. This highlights a complexity within the rights agenda that must be addressed: if individuals have rights, whose responsibility is it to ensure those rights are met (Claiborne et al., 2011)? Currently, in many ways, it seemed that it was the responsibility of the rights-seeker themselves to ensure they acquire their rights, with a few exceptions (e.g., CAL sending list of accommodations to professors). Thus, the process of claiming rights itself is one that has its own structural dimensions and barriers, and the rights agenda will be limited in utility until its proponents can adequately attend not just to the need for rights, but the various complexities required to ensure rights are accessible. In this way, the rights agenda can have limited utility when it becomes removed from the reality of where limitations lie: it is not just about advocating for law and policy change, but seeing such changes through to determine whether their implementation truly results in meaningful positive change for the affected group.

The theoretical framework that informed the conceptualization of our research was that of structural stigma – that stigma is not just rooted in interpersonal interactions, but in laws, policies, and norms that limit access to rights, resources, and opportunities (Charles & Bentley, 2016; Hatzenbuehler, 2016; Livingston, 2013). Throughout our work, we sought to examine the ways in which structural stigma operates at university for students with mental health challenges. Although I offered specific details in Chapters 2 and 3 about structural barriers and their impacts, I will summarize a few overarching points about structural stigma for students with mental health challenges in university here. First, in many ways, it appeared the policies and practices within various parts of the institution, whether it be mental health services, disability services, or educational practices and policies, had the effect of keeping individuals out of services and out of opportunities. In terms of services, this was seen through the number of barriers faced by

participants in both accessing services, or, if access was achieved, in the lack of applicability and effectiveness of the support they received. Though not a focus of this dissertation, it is highly likely that individual access barriers are related to a broader lack of institutional support in terms of funding, staffing, and attention to ensure that such supports are in place and effective. Indeed, through my past work as a practicum student at the university's counselling center, I can attest that there were several practices related to client services that were driven by institutional constraints as opposed to client needs. Here, structural stigma can be seen by the devaluation and lack of support for services and efforts for individuals with mental health challenges. In some cases, certain institutions may be perpetuating structural stigma, as with the university's disability services, which segregates individuals with mental health challenges to receive special help only after their experience is ratified by a professional. This maintains problematic hierarchies wherein professionals define experience for individuals and, through the provision of accommodations, de-prioritize broader accessibility efforts by addressing disability on a case-bycase basis. In this way, disability is constructed as "less than," and the belonging of students with mental health challenges is qualified. This may contribute to the experiences of prejudice and exclusion within learning environments that participants in both studies highlighted.

Second, it was clear both within our survey and focus group data that discriminatory and negative interpersonal interactions were an important mechanism of exclusion among participants. Though structural stigma is embedded in policies and norms, it is often enacted through the professional practices of institutional agents (e.g., professors, administrators, and service providers; Livingston, 2013). Practices that are recurring, that are condoned by leadership, that signify problems of organizational culture, and that are not rectified over time indicate structural stigma. Although our research design does not allow conclusions about all the

above characteristics of structural stigma as enacted through professional practice, the pervasiveness and similarity of experience between participants in discriminatory or negative interpersonal interactions supports the idea that such practices are rooted in structures. Across both studies, participants shared direct experiences or dehumanization and discrimination.

Further, in the World Café participants described a pattern of inconsistency of relationships when seeking support, which acted as a deterrent to pursuing support as participants were repeatedly risking exposure to harmful or unhelpful interactions. This apparently common institutional practice of requiring individuals with mental health challenges to be involved with an evershifting roster of professionals who range vastly in quality and attitudes can thus be seen as another professional practice aligned with structural stigma. This is of particular concern as such individuals act as gatekeepers to students receiving rightful supports.

Participants highlighted that mental health challenges themselves were not considered in service design. Specifically, participants experienced barriers to accessing support for their mental health because those services were designed in such a way that did not consider the needs and challenges of such individuals. In this way, structural stigma operates through invisibility: even when supports are available for individuals with mental health challenges, the reality of mental health challenges is not accounted for within services. Instead, individuals must demonstrate the very skills and capacities which they may be seeking assistance for to be accepted for support.

Finally, structural stigma impacted individuals differently based on other aspects of marginalization and the structural stigma associated with such aspects of marginalization. This aligns with conceptions of intersectional stigma: that stigma is experienced differently and has different impacts based on the presence of multiple different stigmatized identities (Turan et al.,

2019). For example, students experiencing greater financial stress reported greater impact of a variety of structural barriers including service navigation and financial barriers, whereas racial minority students experienced greater barriers related to lack of cultural representation and coercion into services. As was discussed in Study 1, such barriers are related to larger social issues related to classism and racism in university, and thus the structural stigma of mental health challenges does not exist in isolation, but interplays with structural stigma based on a variety of identities and social locations (Bennett et al., 2022).

In sum, structural stigma towards individuals with mental health challenges may be seen as an overarching experience in the lives of students with mental health challenges and, in some cases, appears to be central to how universities operate. Though our most in-depth investigation focused on the presence of structural stigma in relation to self-advocacy for students with mental health challenges, our investigation also highlighted the ways in which structural stigma exists in the policies and practices of services, and how it exists within learning environments. Given our findings, further in-depth investigations into the specifics of structural stigma within health and mental health services, disability services, and academics, and how the structural stigma of mental health challenges intersects with other forms of structural stigma, are certainly warranted. Given that we focused on the individual perspectives of current and former students, it would be valuable for further investigations to collect multi-level perspectives including students, staff, and administrators, and engage in formal policy analysis, to determine how and why structural stigma for students with mental health challenges in university continues to operate as it does.

#### A More Generative Word

In light of this ongoing pervasive structural stigma, and the limitations of both the rights and services anti-stigma agendas, I found myself searching for a way to move forward. How to

think about these results, and how to chart a path forward, for myself personally, for other individuals in positions of power, for institutions of higher learning, and for further research in this area? Harney's (as cited by Nelson, 2022, p. 12) writing suggests another way: "It's not that you wouldn't owe people in something like an economy, or you wouldn't owe your mother, but that the word 'owe' would disappear and it would become some other word, it would be a more generative word." It is this more generative style of thinking that is needed to truly effect change on what we established in this research as serious and, at times, seemingly intractable problems. To think and act generatively is to focus on what could be created in a university that truly valued the presence of students with mental health challenges, rather than thinking in terms of what is needed to disappear mental health symptoms, as in the services agenda, or what is owed to students with mental health challenges, as in the rights agenda. Such thinking would still involve both the provision of rights and services, but in a way that is rooted in the value of creating supportive environments. Of course, this work itself owes a great debt to scholars with lived experience of Madness or mental illness, as well as the current and former University of Victoria students with mental health challenges who participated in this research, and the research team who worked alongside me. I saw time and again that lived experience in the research process enables asking different questions and constructing a different reality of the "problem" of mental distress in society today, and crucially one that addresses many of the limitations discussed previously. These contributions to change make me think of Dolmage (2017, p. 94), who writes, "What if the college or university is the key space, the key economic mechanism, where disability is delayed, discouraged, and diverted from changing the world?" Such questions excite me insofar as they evoke all that could be created if we, collectively, were to truly take seriously the creation of equitable space for students with mental health challenges.

At the same time, it is not only the fostering of disabled scholars and ideas with the potential to "change the world" that could be generated. There is inherent value in accessing an education, no matter what one does with it, including broadening one's perspectives, understanding more of the world around us, developing knowledge of one's own passions (and one's own dislikes), forming relationships with peers both alike and unlike oneself, not to mention the value of greater employment opportunities and social capital, which can empower individuals in various ways and protect against adversities. Thus, one should not have to do anything particularly world-altering in order to deserve access to a high-quality education. There is plenty that can be generated within individuals and communities on a smaller scale when education is made accessible.

Furthermore, individuals with mental health challenges face serious issues in the realms of healthcare, employment and housing. Access to equitable education is an integral part of those issues, and many of the problems we see in education re-create themselves in similar ways in these other domains. Thus, just as these problems overlap currently, it stands to reason that their amelioration may also overlap, suggesting a broad range of social goods that could result from increasing accessibility of education, thus building on the possibilities for generation available.

### Generative Solutions: Re-conceptualizing Challenges as Rooted in Community

Thinking generatively does not just involve lofty daydreams about educational utopian societies, however. It also involves working at concrete changes in our thinking and action. If educational equity is to be realized, one such change is to think of students with mental health challenges not as a problem for professionals to solve by amelioration of symptoms or rendering of appropriate accommodations, but as a problem situated within the university community.

Aligned with this, disability justice approaches call for environmental transformation rooted in

collective change (Bennett et al., 2022). As we found in this dissertation, specialized services such as counselling and disability services were inherently limited in the support that can be given to students. Although some may argue such supports are not inherently limited, but rather limited in terms of lack of funding, lack of professionals, and lack of adequate training, my perspective is that such limitations are, indeed, inherent. As I have quoted elsewhere, I align with Sarason's (1974) perspective that: "As long as mental health problems are defined in ways so as to require the service of professionals there is no solution. When defined in this way the discrepancy between the number of professionals and those deemed to need their service is scandalously large" (p. 189). Again, from my experiences both as a student clinician in public services and from this dissertation, it is clear that we are nowhere close to meeting the needs of individuals with mental health challenges through formal services. From multi-year waitlists to appointments that are too infrequent to realistically be of any therapeutic benefit, to those who report more specialized needs and desire services that are even more rare and challenging to access (e.g., eating disorder specialized services), I cannot imagine what a world would look like where the mental health services provided were truly sufficient to meet the needs of the population, both in volume of support and types of support available. This is not to say that all such services should be eliminated, or efforts for expansion forestalled, but that a sole focus on solving the problem of mental distress in terms of services rendered will not succeed. In what follows, I use concepts and ideas from Sarason's (1974) work The Psychological Sense of Community: Prospects for a Community Psychology to frame potential solutions that originate from a stance that the situates mental health in university as a community, as opposed to individual, problem.

In Sarason's (1974) critique of ostensibly "community-based" mental health services, he writes:

And yet these centers were set up because they were seen as being able to give more service to more people than ever before. Never was there less basis for the promises of a program. I do not wish to suggest there was any deceit; it would be a less serious problem if that were the case. What was involved was the complete (and I am afraid it was complete) inability of the professionals to redefine the problem so as not to require the services only, or even largely, of the traditionally trained professional. (p. 189) portant, then, to take up this challenge of redefining problems away from solely involvement. Such a re-definition means not centering solutions that rely solely on

It is important, then, to take up this challenge of redefining problems away from solely professional involvement. Such a re-definition means not centering solutions that rely solely on expansion of existing services (e.g., hiring more counsellors or CAL advisors), though it is worth noting that participants in our research did advocate for these solutions. I am more interested in how struggles of individuals with mental health challenges in university can be conceptualized as community problems, with community solutions. I offer some potential reconceptualizations and accompanying solutions in what follows, based on what we heard from participants and what I have experienced over my years as a university student. These are attempts to exemplify what it may look like to "redefine the problem."

First, the university can still be conceptualized as a community which, at its core, is competitive. University is not a site with the aim of educating the population as a whole, but rather at identifying and separating the academically strong from the academically weak (Dolmage, 2017). Rather than assist those students who are struggling to develop and improve, low-performing students are rarely acknowledged, reached out to, or meaningfully assisted. This is not to suggest that students with mental health challenges are inherently low-performing.

Although also not meaning to imply that competition itself creates mental ill-health, I do wonder about the limitations of a community in which one's value as a community member is largely defined by one's performance; how one relates to professors and peers, the types of opportunities one has or does not have in the community, all hinge on the extent to which one performs academically. This makes university a different type of community than, for example, a neighbourhood, or even to a degree a workplace, given that the level of formal evaluation and comparison within a workplace is often much less than at university, where students may be tested and compared every few weeks. In line with this, we heard from our participants in both studies that one of the key features of the university community that underlies barriers is the culture that prioritizes productivity and academic success over all else. We heard stories of individuals amid psychiatric hospitalizations and grief where their primary concern remained how their grades would fare in such a situation. It is worth asking, then, what impact this community-level issue of earning a valued status based on performance does to the health of that community. If community members are jostling for limited spots at the top, and trying to avoid being the ones who are ignored at the bottom, how does this influence their priorities? Their actions? The way they interact in that community? To what degree does this dynamic create the skepticism students with mental health challenges face when attempting to access rightful supports? To what degree might the scarcity of supports play a role in maintaining the university as a place for the elite, weeding out potential competition?

The re-defining of the problem in this way calls for solutions that have little to do with mental health services specifically. For example, one might seek to change standards that class averages must be around a certain (usually somewhat low) number, which may incentivize or require that professors let some students flounder to ensure their class average falls within the appropriate range. Certainly, there is little career incentive at this time for instructors to work towards the success of all their students. One might also re-structure how opportunities are offered in university so that, while grade performance might be one arbiter of opportunity, opportunities may also be available based on things such as identity and lived experience, interest, or explicitly as a means to help engage and offer more support to students who may be struggling academically. Here, I am not promoting a model where "everyone gets an A" or everyone succeeds uniformly. Individuals are going to have different interests and abilities, and part of finding one's path is figuring out what those are, which can at times be a difficult lesson. What I mean to suggest here is that, at present, there is little to no investment in students who, for various reasons, are not high-performing in traditional university evaluation, and that such a lack of investment creates a culture that is harmful to everyone by creating an omnipresent risk or experience of devaluation and invisibility if one cannot perform. Thus, solutions that shift community valuation away from solely academic performance may improve the health of the community overall, and of individuals with mental health challenges specifically insofar as they are no longer sent the message that grades and productivity must be prioritized above all else in order to be valued.

Second, there is ongoing segregation of students who experience mental health challenges from students who do not. At times, this segregation is literal, as when accommodations require students to go to a separate space to write their exams. This segregation also occurs more perniciously, enforced by way of instructors receiving information about some of their students' specific needs (i.e., those who are registered with CAL), and not others. Though intended to be helpful to students with disabilities, this also represents a community problem insofar as the identification of "special" students with "special" needs to be

accommodated implies that accessibility is a secondary concern that need only be applied when a disabled person can be identified, as opposed to a priority for the community. If the community consensus is that disability operates a bit like the game "whack-a-mole," in that, when it appears, an accommodation should be slapped on to make it go away (Dolmage, 2017), then the community will always be limited in terms of what it can offer. The incentive to learn and practice methods of instruction that are accessible in terms of allowing students to learn in different ways, and to demonstrate their knowledge in different ways, is minimal when accessibility is conceptualized as an individual, case-by-case undertaking. This is, in effect, my experience of university, where, despite there being offerings and intermittent discussions of universal design approaches to learning and assessment, in practice there is no urgency to embrace these methods. The implicit message is that diverse learning needs are being handled elsewhere, through accommodations. This is problematic practically, as was seen in the current dissertation that not all students with mental health challenges know about or are able to acquire accommodations. It is also, again, a community problem to the extent that this segregation communicates a message of qualified belonging of some members: university is designed for some and accommodates others.

Here too, this problem dictates different solutions outside of formal support services.

Most obviously, it suggests the need to educate and incentivize instructors to make their classrooms accessible in terms of learning and evaluation. This solution, too, undoubtedly has its own structural challenges. I have taught several undergraduate classes, and know from this experience alone that there is not time embedded in instructional hours for learning and experimenting with new methods of teaching. Further, one must also attend to what is considered when hiring professors at institutions. To what degree are teaching skills, and especially those

related to accessibility, prioritized alongside those associated with research? Are such skills incentivized in terms of tangible career reward and advancement in the same way that achievements in other areas are? My sense is that teaching is not valued in the same way. Thus, when I say that one solution is prioritizing developing instructors that prioritize accessibility in their teaching, it would require concrete changes to what the community values and how it is structured, and an allocation of time and resources to build the capacity to teach in this way.

Third, participants noted an overall sense of isolation that was harmful to their mental health and their overall connection to and understanding of university. Participants commented on having little to no connections at university with peers or professors. This contributed to a sense of isolation, and made it challenging for participants to understand their experiences; were their struggles due to their own personal failure and unique to them, or were they shared among their peers? Within our workshops, participants expressed disappointment and sadness at feeling like "just a number." In contrast, participants cited experiences where they had the opportunity to be in smaller settings as beneficial for their sense of connection to university, with several commenting on relationships formed within small classes and smaller departments at the University of Victoria. In these cases, participants were able to develop more relationships with peers, instructors, and administrators, and thus also outlined experiences where their personhood was recognized and their presence valued.

Thus, fostering smaller environments represents another approach to addressing the mental health needs of the university population without explicitly involving mental health services. The most straightforward way to achieve this would be through capping class sizes at smaller numbers, thus allowing students more opportunity to connect with each other and instructors. This, incidentally, would also likely assist with the issue of accessibility in education,

as smaller numbers of students per class may allow instructors to better foster relationships and understand their students' needs, and allow them to make use of more flexible evaluation methods as opposed to those that are often used in larger classes due to the efficiency necessary to generate grades for large numbers of students (e.g., multiple choice exams). Such a change may require re-structuring of how certain departments are run, and hiring many more instructors, which may not be a readily feasible option.

In lieu of this, there are other, less resource-intensive approaches. For example, universities could make use of developing "Learning Communities," which bring together students who are registered in the same large classes into a smaller, separate weekly group to form connections with each other and develop skills to support success at university (e.g., study skills, writing skills). The University of Saskatchewan has used this model for first-year students, and makes use of peer mentors as facilitators of weekly meetings among students in these communities, thus reducing resource burden and offering valuable opportunities for upper-year students to form connections and contribute positively to the university community (University of Saskatchewan College of Arts and Sciences, n.d.). The format of these specific learning communities is academics-based, but such communities could be defined in other ways. For example, they could be comprised of students registered with the Centre for Accessible Learning, and have a disability rights-specific focus. These communities could also be a place to address other community deficits such as a lack of culturally relevant supports and service providers, as was identified by racialized students in Study 1, by forming communities specifically by and for racialized students. Such a solution rests as well on the potential to shift university culture away from a sole focus on productivity, as discussed earlier, so that students can be supported to invest in activities that are not directly academically relevant (i.e., they

would not get any course credit for participation), but that support connection to the university community as a valued aspect of experience.

Further, even within large classes there are teaching approaches that can foster connection. For example, the Psychology of Diversity course at the University of Victoria is a large class of approximately 200 students, but makes use of splitting students into "families" and groups of families called "neighbourhoods" for regular discussion during class facilitated by a teaching assistant, thus facilitating consistent connection in a large class setting. Just as with approaches to foster accessible education, there is a large body of already existing approaches to fostering connection and engagement among students in large classes (e.g., Christopher, 2002; Rocca, 2010; Wilson, 2012). Here again, then, the implementation of such techniques does not necessarily rest largely on ingenuity or developing new knowledge, but on incentivizing instructors to prioritize engagement and connection between students in their classes. This, once again, would require a larger university prioritization of community which allows instructors to spend adequate time on learning and utilizing these techniques.

Finally, another university community problem that could potentially influence the overall health of the community is power differentials. Again, unlike neighbourhoods, university communities differ due to the presence of strict hierarchies: administrators, instructors, university staff and service providers, and students all exist within a web of power relations. Thus, the community is complex in that, although some parties may see a need for change within the community, they may not be in a position to actually execute that change, and may in fact need the approval of someone in the hierarchy who may or may not have the same depth of understanding of the issues at hand. Not only does this make it more practically difficult to execute change, but it also has the potential to harm overall sense of community. Participants in

Study 2 of this dissertation commented on a desire for increased transparency as to how and why the university system works as it does, and increased opportunity to provide feedback that would be taken seriously. This was desired not only for the practical purposes of being able to contribute to change, but also because some participants felt such transparency communicated greater respect and value towards them as community members. As a community member, if one does not understand why certain decisions are made and does not feel they have any power over their experience of that community, one could become disillusioned and disconnected.

Thus, another approach to improving the mental health of the community could be a focus on fostering more transparent, respectful, and trusting relationships within the community. This approach differs from previously discussed approaches in that it could be undertaken both within the university community in various ways (e.g., in relation to learning, class offerings), but also within support services. Essentially, participants expressed layers to their frustration at university, first because they, for example, were shut out and turned away from different services, supports, or opportunities, and second because they felt that being shut out meant they were not valued or cared for within the community. Certainly these reasons could have been the case for negative interactions within services, but at times they could be misunderstandings. For example, several students commented on the delays and infrequency of counselling appointments conveying a message that their concerns are not taken seriously by the counselling centre. From having formerly been a practicum counsellor at this centre, I know that such delays are due to the over-taxed nature of the service: I remember clearly the anxiety of seeing my schedule fill up weeks in advance, knowing that a client needed to be seen sooner than three or four weeks away, but simply having no availability, and I remember feeling this way about nearly every client who crossed my path. Discussions of the limitations of the centre and how challenging it can be to

continue our work despite our own structural barriers to providing the type of service we want were commonly discussed among practicum counsellors and counselling staff, but were not portrayed to the clients seeking services. One wonders how the relationship between the counselling centre and the student community would differ if there was greater transparency of the centre about its limitations and frustrations with those limitations, as opposed to the more closed off nature of the centre presently, where students are left frustrated at their perception of being discarded and uncared for within this service. Might there be a sense of solidarity, as opposed to adversarialism, that could be cultivated by such transparency? Might having this knowledge, as well as the opportunity to meaningfully contribute to change, foster a greater sense of community among those who seek to use such services? Might such involvement improve the useability and applicability of the services themselves (Bennett et al., 2022)? Such shifts would again require shifts in university culture around ideas of power and professionalism: some may feel that it is inappropriate or threatening to include students in understanding how and why decisions are made within the university. However, if the value can be seen in distributing power, both in how this fosters a greater sense of community, and allows for a greater diversity of perspectives to contribute to solutions on community problems, transparency becomes a necessity.

The preceding suggestions are not meant to be extensive, and certainly would need more development and discussion if they were indeed to be attempted within a community. I provide them here as examples for how to, as Sarason (1974) advocates for, redefine mental health related issues at university beyond problems and solutions that are defined in terms of mental health trained professional involvement, and instead as community problems. Part of defining these issues as community problems is that the focus of solutions drifts away from those that

may specifically and solely benefit individuals with mental health challenges towards community-level solutions that, by definition, benefit the community as a whole. Some may be concerned that, in such community-based solutions, the specific needs of individuals with mental health challenges are lost or amalgamated into larger community needs. I do not believe this is necessarily the case, and attempted to create suggestions above that, though their aim would be to benefit community health, would be grounded in specific concerns of individuals with mental health challenges as vocalized in this dissertation (e.g., accessibility of learning, productivity culture). I would also reiterate that if one is truly to adopt a community-level perspective on mental health, then one must see that the health of individuals is inseparable from the health of the community. At the same time, I would not advocate that the approaches I have outlined here be the *only* approaches for addressing mental health challenges in university. There are undeniably specific needs of individuals with mental health challenges that can only be addressed by focused efforts with this subgroup within the community. However, I feel that such approaches are already how mental health problems are typically thought of and addressed at university, and thus offer this community-level perspective in an effort to expand possibilities. These community-based solutions also align more closely with the idea of finding a "more generative word" as discussed in the previous section. Such solutions do not require the disappearance or separation of students with mental health challenges to the degree that more specific solutions often do, and thus suggest exciting possibilities for full inclusion to be realized.

It is also worth mentioning that what I have engaged in within this section is largely speculation on what types of community-based solutions may be possible and helpful based on what we heard from participants. Such speculations also necessitate a different research agenda. Once again referring to Sarason (1974), he writes:

If one looks at a community in terms of people, there is a good deal one can learn about it: the groups that comprise it, their interrelationships, how and at what they work, their recreational activities, their modes of transportation, and so on. But if one stops there, as most of us do, we cannot become aware of "background factors" until changes in them force us to recognize, first, their existence, and, second, their structure. (p. 148)

In this regard, this dissertation has not taken a community perspective insofar as we have focused on the perceptions of individuals on the concrete, immediate issues that impact them. This approach has value, but future research will need to go beyond this to further investigate these background factors which create the more proximal problems which were discussed in this dissertation. Such approaches may involve looking at background factors such as how funding in universities is distributed, the influence of the geographical location of buildings, and the influence of systems within the larger community where the university stands, such as health systems, transportation systems, and housing. The examination of such background factors is important, as we identified in Study 1 of this dissertation that, for example, barriers for students with mental health challenges were inequitably distributed among those experiencing greater financial strain. In this way, structural issues related to mental health challenges in university are also undoubtedly linked to intersecting community issues such as affordable housing. Within the university community, a method such as network analysis may also be used, where data can be collected for each relevant institution within a community, and mapped to demonstrate how different institutions link together, the amount of influence different agencies have, and the prominence of each institution within the community (Fuller et al., 2007; Luke, 2005). Such methods better capture the context of the community, and thus inform about potential points of intervention or need at the community level.

Such approaches also necessitate evaluation of any changes to the community, both intentional and unintentional. For example, the University of Victoria recently moved both Health and Counselling Services to the same building which exists outside the "ring," the road that encircles the area of campus where most campus buildings are housed. This was done with the intention to better integrate health and counselling services. Evaluating the extent to which this integration impacted the community in the positive way intended, and the extent to which shifting these services further from the centre "hub" of campus impacted student use of this service, is also important. The same is true for any of the community shifts I described above: if, for example, learning communities were implemented, to what degree do such communities foster greater connection between students and to the broader university community? Which components of these communities are responsible for such shifts? In what way could learning communities be improved to be more effective at engaging students? In this way, evaluation is essential to ensure that changes made are done so with a community-engaged spirit to the extent that they remain responsive to community feedback and flexible to make changes to better support the community.

## Taking Action: Successes, Complexities, and Charting the Path Forward

Our Process and Plans for Action

Our project has not ended with the research process, but has continued, shifting our focus towards taking meaningful action based on our results. Our research team is pursuing collaborations and relationships that could help make some of the ideas discussed in this dissertation a reality, albeit some of the smaller, more immediately relevant ideas. This itself was a challenge for me: our team began discussing what actions for change we should take based on our results around the time I was writing the analysis for Study 2 of this dissertation. During this

writing, I was focused on large systemic limitations and was feeling the powerlessness of affecting change at the systemic level in a short period of time. Here, I was lucky to have my research team who told me quickly, clearly, and firmly to, in gentler words, "snap out of it." Through my writing, I had fallen into the trap of the removed researcher who was becoming so wrapped up in the problematic underlying philosophy of why universities exist the way they do, and was feeling powerless to do anything that would clearly make an impact in this regard (Guy, Feldman, Cain, Leesman, & Hood, 2020; Reason et al., 2011). Through discussions among our research team, I was reminded that students with lived experience do not this luxury: they are trying to get through university right now with goals and ideas of their own, and right now they are doing so without adequate resources to understand the services available, what they are for, and how to access them. And, despite the many limitations noted to the current system, we did have some participants discuss how they had been helped by being able to access services at the university. Thus, one complexity of action was illustrated clearly to me: although as a researcher one may feel the need for larger systemic changes that take place over years and decades, one must consider the potential costs of solely focusing on such changes at the expense of the more immediate concerns of the community (Guy et al., 2020; Reason et al., 2011).

Our group returned to the more short-term suggestions for change made by participants, and discussed our options in terms of what our team could feasibly accomplish, what resources already existed in some form and which were missing, and what ideas excited us as a team. We settled on the idea of creating an interactive resource map for students. This map would create a centralized hub of resources for students, where they could view everything available to them in one location, and compare between the different resources to understand which specific resource may make sense for them to access at this time. We would provide access information, including

contact information and any supporting documentation the student may need to access the services. Links to service websites would be included so that students could seek out more specific information as needed. Being a map, our resource would also convey where on campus certain resources were located. The map would include not only mental health related support services, but also student support services in general, honouring the connection our participants made between their mental wellness, social wellness, and academic wellness, and thus attempting to inform about resources relevant to all of these domains.

After deciding on creating an interactive map, our team stumbled on an interactive map that already existed at the University of Victoria. The map focused on providing information for the university's Facilities Management, and contained information such as where recycling bins are located, accessibility information such as wheelchairs and ramps, and, when zooming in on buildings, where specific classrooms were located within buildings (Neal et al., n.d.). I contacted the project manager of this map, Dr. Jessica Neal, to discuss the steps involved in creating a map such as this, and was pleasantly surprised that she was invested in our idea, and coordinated an opportunity for our map to be integrated with the already existing map, and for us to collaborate with her and an undergraduate geography student to create the map itself. This illustrated for me that, when taking action, finding people to champion a project is essential for its realization. Not only does this collaboration allow for our team to focus our efforts on this project within our own skill-set (i.e., writing about and defining various support services on campus) as opposed to learning an entirely new set of skills (i.e., GIS technology, mapping aesthetics), it also allows for the project to be more financially sustainable and better integrated with what already exists at University of Victoria as opposed to an outside effort (i.e., rather than our team paying to host the map on a separate website, it can be integrated into the costs and platform already funded by

UVic). This collaboration for the creation of a student support services interactive map is currently underway, with expected completion in early 2023.

## The Complexity of Action

At the same time as collaboration can expedite and improve the quality of projects, our team has discussed the complexities of institutional involvement in executing a project that operated more from a peer perspective. The benefits to working with institutions are clear: beyond what was discussed previously in terms of access to greater skill-set and infrastructure, there are also some desired changes that participants expressed that our team simply could not accomplish, as the issues are situated within institutions themselves. For example, participants desired general changes such as greater outreach of services and changes to specific processes, such as the administration of walk-in appointments and the intake process for CAL. It is only within these institutions that such changes are feasible, and there would be important stakeholder perspectives within these settings that may provide more important information about barriers that we could not see from our perspective that may impact the execution of these changes.

On the other hand, institutional partnership has its downsides. As highlighted by our participants and discussed within our own team, peer-led efforts which take place outside of the university system can often be quicker to execute and freer from institutional constraints on what can be offered. For example, our original idea for our interactive map also included a component where students could add feedback, reviews, and advice about accessing services to the already existing information in order to provide students not just the institutionally-sanctioned facts about the service, but also the user perspective. Our decision to collaborate with the institution led us to let go of this aspect being integrated directly into the map, as we were concerned about the level of control of information that the institution would need, and that an honest and

complete student perspective would not be allowed to be conveyed. Instead, we have discussed moving this portion of the project to be based on the UVSS Peer Support Centre website, and have the link to this forum provided within the map. This is one example of how institutional collaboration has the potential to "sanitize" both the issues expressed by our participants as well as the accompanying solutions. Thus, although it is exciting and validating to have institutional interest in our work, and in some cases will be necessary in advocating for change, we remain mindful that the result of too much collaboration in this regard may end up being used as evidence that the university is listening and making changes, while at the same time risking minimizing the severity and urgency of system-related concerns. Since we are just transitioning to working towards change, this is an ongoing dynamic to keep in mind going forward.

Another complexity to action our team has noticed is that it is not just the act of creating a resource that is sufficient to count as action. As Sarason (1974) writes:

The complexity of a community will in large part determine the fate of efforts to change that community in any respect... What happens [to change efforts] will in large measure be determined by the degree to which it is based on a realistic conception of the complexity and distinctiveness of that community (p. 131).

The step of creating *something* with the aim of fostering improvement is relatively straightforward, but the processes of both choosing what to create and the step that follows creation, ensuring the population of interest knows about and can easily use the resource, are more complex, and involve a deeper understanding of the community.

Our team has especially noticed the importance of this latter point of implementation as we discussed what types of changes we wished to undertake. For example, several participants in our workshops mentioned a desire for an online survey where a student could report on the

specific struggles they are having, and then have narrowed down resources presented to them based on their needs. Such a survey already exists and was created through the UVSS Peer Support Centre, entitled the "Self-Care and Resource Guide" (UVSS Peer Support Centre, n.d.). Indeed, as mentioned previously, peer support services in general were named by many in our workshops as desirable, though the existing peer support services at the University of Victoria are vastly underutilized. This is in spite of massive amounts of effort spent by this organization to promote their services, including the Self-Care and Resource Guide, via in-class announcements, social media, and posters around campus. Thus, creation of resources is one step to taking action, but the implementation of those resources, such as how to communicate their existence to students, how to convey to students their utility and trustworthiness, and how to situate those resources within the larger university milieu of existing resources determines to what degree the effort will be successful. An understanding of the student population and the infrastructure of existing resources is important in supporting the success of these endeavours. In the specific case of the discrepancy between expressed desire for and actual utilization of peer support services, it may be worthwhile to undertake focus groups with students discussing barriers to peer support services use, or to integrate the advertising of peer support services along with other, better-known services at UVic. For example, if counsellors are limited by providing infrequent appointments, it may be helpful to have them refer students to the Peer Support Centre, or for professors to make reference to the Self-Care and Resource Guide in classes. Regardless of the specifics of any particular change effort, examples such as this illustrate the importance of, when seeking to act, asking not just what needs to change but how change should be pursued given the unique constraints and opportunities within a community.

Another complexity to change is the extent to which our collective imagination is shaped by the current context. Many potential solutions were generated, both within our research team and by participants. However, it is important to be mindful that these solutions were products of the current system in which we live, and thus were often ways to improve systems that were not working, as opposed to re-envisioning these very systems. I find Sarason's (1974) writing on this helpful, as well:

When periodically the community is made to recognize that the practice is not working, that in fact it often worsens the very problems it is meant to solve, the inevitable result is a resolve to do better what it is already doing. To set about handling the problem differently requires, at the very least, an explication and examination of the values underlying the existing practice – the "should and oughts," usually unverbalized, which govern social relationships and obligations... It [leads] to the realization that the very existence of the institution [can be] symptomatic of a more general problem. (p. 213)

Thus, it seems important to me not solely to take at face value what participants asked for when they asked for solutions, but to think more deeply about the values and assumptions behind those suggestions, and the extent to which the specific ideas for change may more or less effectively foster desired long-term outcomes. For example, if participants' desire is for services to be more proactive and preventative, can this goal be realized through, as many participants suggested "hiring more counsellors?" What are the assumptions of this approach, and what are other ways of looking at the problem of reactive services that would indicate different solutions to achieve the same result of services being more proactive?

It bears mentioning, though, that our own first action of creating an interactive map decidedly does not fall under this "more generative" umbrella of solutions I discussed earlier,

instead focusing on improving what exists currently. Indeed, when discussing ideas for action our team could take, one of our core considerations was feasibility: what did our team have the knowledge, expertise, and social positioning to feel confident that we could actually create and distribute in a timely manner? In essence, we did not feel our potential for action was limitless, but was constrained for the reasons described above and, for most of our team, our transient role as students, where we all planned to move on to different schools, jobs, and, for some, areas of study at some point. Far from being unique to our situation, the "action" in action research is always constrained to some degree, be it for personal reasons related to the research team, or reasons such as cost, cultural relevance, other competing ideas and interventions, or political reasons (Guy et al., 2020; Mosher et al., 2014). Our team decisions related to action illustrates another complexity to action that I feel deeply: it may be easier and more immediately effective to advocate for change that goes along with improving the situation within the status quo, as opposed to posing challenges from outside it, even if such improvements do not necessarily align with one's philosophical stance (but are not in total opposition to it). Thus, the complexity here may be: how does one engage in improving the status quo while also advocating for perspectives that radically re-envision the systems at hand? Should one be engaged in both of these at the same time? For now, I have sat with this issue and, as Sarason (1974) recommends, have attempted to be more cognizant not just of what various solutions may be effective or feasible, but what values and assumptions underlie different approaches. Doing so at least ensures such values are made conscious and can be discussed and weighed, as opposed to being an invisible force that nevertheless shapes the direction of change.

## Ways of Being as a Mechanism of Change

These complexities to action will never be finally resolved, but rather held and negotiated in specific situations in relation to specific actions. However, there are several ongoing ways of being one may align oneself with: not focused on what one does but how one is. The first of these, which feels essential to me, is connection. What I mean by this is that action need not always be building something new, whether it be a program or a resource, but rather doing our own practice in such a way that changes things by virtue of building connection between others. I have come to conclude the value of this both through the evolution of our research team and our World Café from Study 2. In terms of our team, as I discussed previously, the connection that occurred within appeared to me to be at least as valuable as the research we were doing. The greater understanding and empathy we had for the issues at hand through listening to each other, the accountability that came from not just needing to complete this project for the sake of completing it, but also for seeing through the commitments we made to each other, and the way in which our relationships to each other buoyed investment in the project through challenging times were all valuable components of the project that arose from connection. The sense that our team was not just a place to achieve project goals but also a place to belong felt, to me, like the more radical changes I have envisioned to productivity culture, to accessibility, and to the pervasive anonymity in university already realized. The same was true of our workshops, where our team was most thrilled not by the data we extracted, but by what we saw formed between participants: whether it be solidarity communicated, emotions felt and expressed on behalf of others, or cell phone numbers exchanged, the value of connection was undeniable, and I am confident that the rich data from the workshop was possible only in the context of the connection that was present. In essence, what this means to me is that change cannot be sought without

already acting in alignment with the changes one wants to see to the extent that this is possible. If one wishes to conceptualize problems associated with mental health challenges as rooted in the community, then one must seek to create the type of community that could rectify these issues in the work that they do. In this way, one is always "acting" towards the changes one wishes to see by exercising agency over the opportunities that are immediately available to them.

These ways of being in relation to others are inextricable from ways of being oneself.

Here again, I am inspired by Sarason's (1974) words:

I mean to emphasize that precisely because the situation reflects *our* culture, *we* (as individuals and as professionals) have been part of the problem: our ways of living, the theories we hold, and the actions we take unwittingly reflect both the weaknesses and strengths of our culture. The problem is not only "out there," it is in us as well. It is far easier to say this than it is to confront it and work through it. Culture does its job too well to make efforts at transcending it an easy affair. (p. 276)

I appreciate these thoughts as they remind me that such attempts at transcendence is itself an ongoing, lifelong action. I also appreciate the acknowledgment that, although structural change may not always be readily feasible or accessible to certain parties, individuals changing their values, the way they relate to others, and the way they interact with systems can have an impact.

For myself, I can say that this project undoubtedly changed me. I taught four subsequent undergraduate courses over the course of my degree, beginning before I conceptualized this project, and continuing through to when our team was developing ideas for Study 2 of this project. Such experience has allowed me a concrete way to identify changes that have occurred. When teaching before conceptualizing this project, I proceeded much as dominant culture dictated I should: I accommodated those students who sent their accommodations to me, I

lectured to students on the content that had been defined as appropriate by textbooks on the subject (which was, incidentally, a course on psychological disorders of children and adolescents), and I responded to student questions and concerns as they arose. I was unsure whether I was "allowed" to grant extensions without appropriate documentation, and held some of the tacit beliefs that had been instilled in me through my training: to be on guard for students who may be trying to seek unfair advantages, to assume limited potential of students who were enrolled with CAL services, and to assume that issues of disability were being appropriately handled by existing systems. This is in stark contrast to the course I taught most recently, in September 2021, where I structured the learning goals not only in terms of course content, but also in teaching individuals how to identify and communicate their needs and identify healthy work environments, and broadly defined for them what their needs may look like (e.g., "needing a weekend to relax or be with friends" is an acceptable reason for needing an extension). I proactively reached out to students I noticed who may be struggling. I continue to develop in balancing legitimate student need for flexibility with the accountability and structure that some students explicitly ask for to support their achievement. These changes were coupled with changes in course content to focus on underrepresented, often structural perspectives as opposed to those most dominantly represented in psychology, and an explicit focus on creating connection within the class, both between students and with myself and students, as a way to facilitate engagement and learning. Essentially, these were not just changes in what I did, but reflected changes in my own values regarding my views on the purpose of education, how I conceptualized the presence of disability and difference more broadly within the classroom, and how I saw my role in relation to students. I do not share this in an attempt to self-congratulate, but merely to say that I have seen the value of undoing cultural assumptions in my own life: I am a better, more ethical teacher now than I was by virtue of my ongoing connection to this project and to individuals with lived experience of mental health challenges. Such improvements were achieved not by surface level changes in policy and practice enforcing certain standards, but through a personal and careful re-examination of university culture, my role in it, and whether the values that had been instilled in me were aligned with my evolving understanding of university, its structures, and justice.

I recognize that there is perhaps inherent contradiction in closing a dissertation focused on structural barriers with a discussion of how relationships and internal work are the path forward. In fact, I can conjure up a number of somewhat cynical, but warranted, questions from a variety of camps about this approach. Those with lived experience of mental health challenges may ask something to the extent of, "It's all fine and good that you made friends and experienced personal growth, but many, including those who made this project possible, are still struggling. What do you plan to do to help?" From those in power, they may posit something such as, "It's all fine and good that you, personally, are thinking about these issues structurally and at the community level, but what, realistically and in the context of constrained resources, can be done to change things in the direction you seek?" Although I take these questions seriously and have attempted to articulate different possible answers, solutions, and actions in previous sections, to me, an additional important answer, if I am to take seriously my own values and the philosophical underpinnings of this dissertation is, "I am not sure, but I would like to talk about it." It is my view of the essentialness of this uncertainty which leads me to end my dissertation talking about the value of connection and internal change.

Though this dissertation focuses on structural barriers and structural changes, we must not forget that structures are comprised, always, of people. Sandler (2020, p. 319) reminds me of

this when she writes "We are defined by who we deem worthy of investment" (p., emphasis added). Nelson (2007) similarly affirms this through her writing:

I find the grammar of justice maddening. It's always "rendered," "served," or "done." It always swoops down from on high – from God, from the state – like a bolt of lightening, a flaming sword come to separate the righteous from the wicked in Earth's final hour. It is not, apparently, something we can give to one another, something we can make happen, something we can create together down here in the muck. (p. 113)

Both of these writers illustrate a simple point: systemic change is only achievable through the actions of people. If change will happen, it will be because people make the decisions that drive those changes; whether it be through grassroots activism or through the highest levels of institutional power. Indeed, in their writing on disability justice, Bennett and colleagues (2022) discuss the essential role of virtue ethics: when making decisions, we must evaluate the morality of those decisions insofar as they impact accessibility. If people remain disconnected from or exclusionary towards those who have certain lived experiences, then we will not have the perspectives or urgency that is required for such work. Just because problems have been identified, there is no "bolt of lightening or flaming sword" swooping down to fix our systems, it is only what we choose to fight for and create over time. Thus, although changing the way we relate to each other and changing our values and assumptions is not the point at which we declare we are "all done," our successes or failures to make change for the better depend on our ongoing engagement in these regards.

It should come as no surprise, then, that I at times experience frustration towards the pressure that is often put on researchers, and perhaps especially within clinical psychology to "solve" and "fix" the issues we identify. At times, it can feel like the message is "if you want to

take a critical perspective on social issues related to mental health, then you better have a set of well-reasoned solutions that are communicable within the language and metrics of the stillpresent dominant perspective." When I feel pressured to fix or provide a well-defined solution to the complex problems identified, I can feel hopelessly inadequate and destined to fail, and I should. The problems are too complex, diverse across settings, involve too many stakeholders, and indeed too many areas of expertise to assume that they can be simply or finally resolved. Rather, a productive way forward is to have the ideas I have put forward have value and a socalled "seat at the table." There are already a number of considerations taken into account when the "problem" of students with mental health challenges at university is discussed, including economic, academic, liability, and institutional capacity. These considerations are grounded in conceptualizations of individualized distress and treatment. The most immediate and essential way forward, then, is altering how these issues are thought about and talked about. Taking seriously the structural dimensions of suffering and how such dimensions call for a fundamentally different approach, even when the precise action or resolution cannot be identified at the outset is the route in to change. Such a change process is aligned with the concept of "collaborative entanglement," where research findings and perspectives can be used as a starting point for discussion of diverse individuals with the aim of imagining new possibilities for change (Bennet & Bennet, 2006). In this perspective, it is not necessarily making concrete changes that constitutes action, but creating the conditions for change by mobilizing knowledge in such a way that focuses on bringing diverse stakeholders into contact with each other, thus allowing for the proliferation of knowledge and new ideas (Mosher et al., 2014). Such environments create the conditions for new ideas without dictating exactly what the outcome will be (Mosher et al., 2014).

In this way, it is not valuable to come in with all of the solutions, as this undercuts the complexity of the problems at hand, and of the local communities in which such problems must be addressed. As Mosher and colleagues (2014) note, the path of action is one that requires "embracing, rather than resisting, the reality that the path, the destination, and the players are always evolving" (p. 8). Thus, thoughtful and transparent discussions about what underlying values are being adhered to, which considerations and perspectives are prioritized, and what advantages or disadvantages this has is an important starting point to transforming the way such issues are approached. It is not that certain people have arrived at certain perspectives that are infallible and must be adhered to in the name of taking action in the "right" or "best" way that should chart the course of action for years to come. Rather, as individuals and as a society, our perspectives should always be evolving, and it is only through engagement with others' perspectives, values, and ways of being that they do. At this point, it is structural, communitybased approaches that are missing from institutional discussions on mental health in university. Advocating for the inclusion of such considerations will require a great deal of ambition, persistence, creativity, and hope. When I am tasked with answering what is to be *done* about all this, then, I refer back to Nelson's (2021) brief response to Harney's proposition of "a more generative word," where she writes "I don't know yet what this [more generative] word would be, nor am I sure that, if I found it, I would know how to live it. But I feel certain that such querying leads in the right direction" (p. 12). In the end, it is this orientation towards creation, in the absence of having all the answers, that marks the path forward.

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## Appendix A – Study 1 Demographics Questionnaire

The following questions ask about different dimensions of who you are and the nature of the mental health challenges you have experienced. This is important for us to know, as we are interested in how people's experiences of university are influenced by their own unique background and history, as well as by the nature of the mental health challenges they experience. This questionnaire will ask you to share some specific information about the nature of your mental health challenges. Please feel free to skip any question you do not wish to answer or take breaks if that would be helpful.

- 1. What is your current age?
- 2. What is your gender? [open text]
- 3. What is your sexual orientation? [open text]
- 4. Please indicate your identified ethnic background (peoples' ethnicity describes their feeling of belonging and attachment to a distinct group of a larger population that shares their ancestry, colour, culture, language, or religion).
- 5. Does Canadian society categorize you as a racial minority?
- a. Yes
- b. No
- 6. Are you a member of an Indigenous group?
  - a) No
  - b) Yes, please specify
- 7. What is your current occupational status?
- a. Employed full-time
- b. Employed part-time
- c. Work at home/self-employed
- d. Homemaker
- e. Student, full time
- f. Student, part time
- g. Unemployed
- h. Receiving disability
- i. Retired
- j. Other (please specify)
- 8. Are you a citizen or permanent resident of Canada?
- 1. Yes
- 2. No

- 9. Are you a first-generation post-secondary student (that is, are you the first member of your immediate family to go to university)?
- 1. Yes
- 2. No
- 10. How would you describe your current money situation?
- a. Comfortable, with extra
- b. Comfortable, but no extra
- c. Have to cut back
- d. Cannot make ends meet
  - 11. What is your current living situation?
  - a. Without housing
  - B. temporary housing
  - b. Precarious/inconsistent housing
  - c. In university residence
  - d. With parent(s) or guardian(s)
  - e. Off campus, with roommates
  - f. Off campus, with partner and/or children
  - g. Off campus, alone
    - 12. Which n are you enrolled in as a student (or were you enrolled in as a student)?
    - a. Business
    - b. Education
    - c. Engineering
    - d. Fine Arts
    - e. Human & Social Development
    - f. Humanities
    - g. Law
    - h. Science
    - i. Social Sciences
    - 13. What is your major (or what was your major when you were enrolled as a student)?
    - 14. What is your current degree status?
    - a. Currently completing degree
    - b. Former student with completed degree
    - c. Former student without completed degree
    - 15. What year did you **start** attending post-secondary education?
    - 16. (If applicable) What year did you **stop** attending post-secondary education?

- 17. Did you take any leaves from post-secondary education? If so, please indicate which years:
- 18. What is the highest year of school you have completed?
- a. Grade 12
- **b.** One year post-secondary (trade school/college/university)
- **c.** Two years post-secondary (trade school/college/university)
- **d.** Three years post-secondary (trade school/college/university)
- **e.** Four years post-secondary (trade school/college/university)
- **f.** Five years or more post-secondary (trade school/college/university)
- **g.** One year masters/doctoral work
- h. Two years masters/doctoral work
- i. Three years masters/doctoral work
- **j.** Four years masters/doctoral work
- **k.** Five years masters/doctoral work
- **l.** Six years masters/doctoral work
- **m.** Seven or more years masters/doctoral work
  - 19. Which, if any, mental illness diagnoses have you received?
  - 20. Which, if any, mental illness diagnoses have you **not** received but think you may have?
  - 21. When your mental health challenges were at their worst during your time at the University of Victoria, how impactful did you find your symptoms to be?
  - a. Not impactful
  - b. Somewhat impactful
  - c. Very impactful
  - d. Extremely impactful
  - 22. Have you received any additional physical or mental health diagnoses besides what was discussed previously? If so, please list here.
  - 23. Is there a particular diagnosis or set of concerns that most impacts your educational experience?
  - 24. When your mental health challenges were at their worst during your time at the University of Victoria, what symptoms of mental health challenges were you experiencing? Please note: check all where at least one challenge applies (i.e., you don't have to experience all symptoms listed for each option).
- a. Impulsivity, excessive energy or joy, aggression, anger, easily frustrated, thrill-seeking behavior, unhealthy substance use
- b. Self-injury (e.g., cutting, burning, skin-picking, hair-pulling)

- c. Excessive sadness, low motivation, loss of pleasure, low self-worth, self-blame, suicidal ideation, worry (e.g., specific fears or worries, social situations, overarching worry), racing thoughts
- d. High levels of stress or challenges related to experience of trauma/life stress (e.g., flashbacks, hypersensitive to surroundings, nightmares, detachment of reality, "blacking out")
- e. Challenges with body image, extreme weight loss strategies, binge eating, fear of gaining weight
- f. Challenges with social communication, changes in routine, physical touch, attention, concentration or learning, repetitive behaviors/movements (e.g., shaking, body rocking, head banging)
- g. False beliefs of what one is seeing or hearing, disconnection from reality
- h. Uncomfortable physical sensations (e.g., headaches, nausea/vomiting, fatigue, sleep disturbances, fidgety, racing heart, chest pain, dizzy, muscle tension)
- i. Other (please specify)

### **Appendix B - Structural Barriers in Higher Education**

- 0 Not applicable/I have not encountered this barrier
- 1 I was not negatively impacted by this barriers
- 2 I was somewhat negatively impacted by this barriers
- 3 I was moderately impacted by this barrier
- 4 I was very negatively impacted by this barrier

This questionnaire is going to ask you about different barriers you may have experienced at the University of Victoria. Reflecting on these barriers may bring up negative or stressful memories. Please feel free to skip any question you do not wish to answer or take breaks if that would be helpful.

#### CAL Section

Have you ever received services or tried to receive services from the Center for Accessible Learning (CAL) at the University of Victoria?

- a. Yes
- b. No

Which of the following barriers have you experienced in post-secondary education and how much has it impacted you?

- 1. Time delays accessing the necessary services to acquire diagnosis or documentation for the Center for Accessible Learning (CAL).
- **2. Financial barriers** to accessing the necessary services to acquire diagnosis or documentation for the CAL.
- **3.** Inability to receive adequate diagnosis to access accommodations through the CAL.
- **4.** Stress or negative emotion related to the process of disclosing your diagnosis/experience to others for the purpose of accessing academic support and/or accommodations.
- **5.** Fears that acquiring accommodations will negatively affect your marks in class or your treatment/experience within the class.
- **6.** Fears that acquiring accommodations will lead to unwanted disclosure of your experience/diagnosis to professors, peers, or future employers.
- 7. Fear or not wanting a documented mental illness that could have other consequences (e.g., relationships with others, student loans, future career prospects, etc.)

- **8.** Inconsistent implementation of accommodations in courses (e.g., varying accommodation resources applied from one class to another).
- **9.** Lack of follow-up from CAL or instructors regarding whether your accommodations are appropriate/helpful.
- **10.** Negative comments or skepticism from others (e.g., CAL staff, professors, students) about your accommodations.
- 11. Feeling burdened or overwhelmed by paperwork involved in accessing accommodations.
- 12. Being able to access CAL but the accommodations provided are not appropriate/helpful.
- 13. Navigating the CAL services without adequate or appropriate guidance.
- **14.** Discontinuation of support from CAL without consent.
- **15.** Lack of culturally diverse representation in CAL staff.
- **16.** Being assigned a CAL advisor that is not adequate for meeting your support needs.

Are there any other barriers to receiving accommodations through the Center for Accessible Learning (CAL) that you have faced?

What solutions/supports would be helpful in reducing these barriers?

#### **Information Section**

- 1. Lack of knowledge of the role of different professionals in mental health services (e.g., psychologist and psychiatrist, counsellor and registered counsellor, etc).
- 2. Lack of knowledge about available types of support from the CAL (e.g., borrowed laptops, noise-cancelling headphones).
- 3. Lack of awareness that your experience/diagnosis qualified you for academic accommodations through the CAL.
- 4. Lack of knowledge of funding opportunities for students with diagnosed mental illnesses.
- 5. Lack of knowledge about how to access academic support.
- 6. Lack of knowledge about how to access clinical mental health support (e.g., counsellors, doctors, psychiatrists).

- 7. Lack of knowledge about how to access non-clinical mental health support (e.g., peer support, holistic approaches).
- 8. Lack of information shared on medications prescribed during an encounter with a health or mental health professional.

Are there any other barriers to accessing information that you have faced?

What solutions/supports would be helpful in reducing these barriers?

#### **Mental Health and Health Services**

- 1. Lack of counselling services available that meet your needs.
- 2. Lack of psychiatrist services available that meet your needs.
- 3. Lack of alternative or peer-run mental health services (e.g., peer support, holistic approaches).
- 4. Lack of mental health support that is appropriate to your cultural background.
- 5. Feeling pressured into receiving services you would not otherwise access.
- 6. Experiencing time-delays in access to services (e.g., being on a waitlist).
- 7. Lack of follow-up or ongoing support from mental health services.
- 8. Challenges coordinating your care between services or appointments.
- 9. Financial barriers to accessing mental health services.
- 10. Financial barriers in accessing prescribed medication.
- 11. Other barriers to accessing mental health services (e.g., limited hours of operation).
- 12. Hearing negative beliefs or stereotypes about individuals with mental illness from mental health service providers.
- 13. Navigating health and mental health services without guidance.
- 14. Difficulty of the process for accessing and maintaining continued access to care (e.g., paperwork, following up with providers).
- 15. Lack of a spokesperson or advocate on your behalf for accessing mental health services.

16. Lack of involvement in the continuation of services outside of the university (e.g., not getting referrals to other mental health services).

Are there any other barriers to health or mental health services that you have faced?

What solutions/supports would be helpful in reducing these barriers?

### **Trajectories Section**

Have you ever taken extended time off (e.g., withdrawn, dropped out) from university?

- i. Yes
- k. No
  - 1. Lack of social support upon returning to academics after leaving and returning to school.
  - 2. Lack of financial support upon returning to academics after leaving and returning to school.
  - 3. Lack of practical support (e.g., with navigating registration, submitting appropriate paperwork) upon returning to academics after leaving and returning to school.
  - 4. Feeling burdened or overwhelmed by paperwork involved in returning to academics after leaving and returning to school.
  - 5. Financial challenges due to being enrolled in university for longer than anticipated (e.g., losing access to financial supports after a set number of years).

Are there any other barriers related to your pathway through university that you have faced?

What solutions/supports would be helpful in reducing these barriers?

### **University Culture**

- 1. Barriers related to learning in the "typical" university classroom (e.g., busy lecture halls, set lecture times).
- 2. Barriers related to "typical" university evaluation (e.g., timed tests, strict academic schedules/due dates).
- 3. Others' beliefs that you are "faking" your experience in order to receive special privileges.
- 4. Lack of privacy or increased surveillance due to your experience/diagnosis.
- 5. Stress or negative emotion related to the process of disclosing your diagnosis/experience to others.

- 6. Hearing negative beliefs or stereotypes about individuals with mental illness (e.g., that individuals with mental illness are unfit for certain professions, that they exaggerate their symptoms to get special privileges) from **university faculty or staff.**
- 7. Hearing negative beliefs or stereotypes about individuals with mental illness (e.g., that individuals with mental illness are unfit for certain professions, that they exaggerate their symptoms to get special privileges) from **other students.**
- 8. Having others assume unrelated issues or concerns are associated with one's mental health challenges.
- 9. Expectation of being your own advocate in health or mental health services.

Are there any other barriers related to the culture of higher education that you have faced?

What solutions/supports would be helpful in reducing these barriers?

### **Open-Ended Questions**

Are there any other barriers you have faced that have not been previously addressed?

What strategies or supports have you found helpful in navigating post-secondary education?

# Appendix C – Short-Form 36

\*As we were interested in the impact of mental health symptoms, only those items from the SF-36 which pertained to impact of mental health were included (i.e., we did not ask participants about items related to physical health).

The following questions ask about how your mental health has impacted your life and academics. For these questions, we are asking you to reflect on how you were impacted wh

your mental health was at its worst or lowest point during your time at the University.		
1. When your mental health was at its worst during your time at the University of Victoryour mental health:	oria, w	vas
a. Excellent		
b. Very good		
c. Good		
d. Fair		
e.Poor		
When your mental health was at its worst during your time at UVic, did you have any of following problems with your work, academics, or other regular daily activities as a response your mental health (such as feeling depressed or anxious)?		
	Yes 0	No 1
17. Cut down the <b>amount of time</b> you spent on work or other activities		
18. <b>Accomplished less</b> than you would like		
19. Engaged in work or other activities with less attentiveness or carefulness than usual		

20. When your mental health was at its worst during your time at UVic, to what extent did your mental health interfere with your normal social activities with family, friends, neighbors, or groups?

- a. Not at all
- b. Slightly
- c. Moderately
- d. Quite a bit
- e. Extremely

These questions are about how you were feeling when your mental health was at its worst during your time at UVic. For each question, please give the one answer that comes closest to the way you were feeling.

When your mental health was at its worst during your time at UVic, how often...

All of	Most of	A good bit	Some of	A little	None of
the	the time	of the	the time	of the	the time
time		time		time	

- 23. Did you feel energetic or lively?
- 24. Were you a very nervous person?
- 25. Was your mood so low that nothing could cheer you up?
- 26. Did you feel calm and peaceful?
- 27. Did you have a lot of energy?
- 28. Did you feel discouraged and sad?

30. Were you a happy person?
31. Did you feel tired?
32. When your mental health was at its worst during your time at UVic, how much of the time did your mental health interfere with your social activities (like visiting with friends, relatives, etc.)?
a. All of the time
b. Most of the time
c. Some of the time
d. A little of the time

29. Did you feel burnt out?

e. None of the time

### Appendix D – Workshop Format and Questions

#### Session 1

#### Overall Schedule:

- 1:00 Introduction and initial self-reflection
- 1:30 break
- 1:40 introduction of group guidelines and first group question
- 2:15 break
- 2:25 second group question
- 2:50 break
- 3:00 third group question
- 3:30 break
- 3:40 self-reflection time and wrap up

### Part 1: Introduction and Initial Self Reflection – 30 minutes

KARI – Welcome and gratitude, discussion of topic of self-advocacy and our project, instructions for pronouns (Zoom and/or in-person) (~5 minutes)

TEAM – team introductions (~12 minutes)

KARI – Consent overview (~3 minutes)

KARI – Leading through self-reflection activity (~15 minutes)

- 1. Draw a small circle in the center of the page with your name on it.
- 2. Then, draw circles all over the page with all the different types of services and supports you've tried to access during your time at UVic they could be services inside or outside UVic.
- 3. Once you have your circles drawn, grab **two colours** of marker.

  With one colour colour in the circles of all the supports you access
  - With one colour, colour in the circles of all the supports you accessed that you **found** helpful and that met your needs.
  - With the other, colour in the circles of the supports you accessed that **did not meet your needs** or were negative experiences.
- 4. Finally, think about each of these experiences individually from each other. Did anyone advocate for you when you needed that support? Did you talk to a friend or family member before or after the appointment to get advice on what to say or to debrief what was said? Did someone help you reach out to the service? Did someone come along with you? Did someone help you follow up or check on how things went? Think about family members, friends, peers, profs, or even other service providers. If so, write their names (roles?) in little bubbles around each service.

## Part 2: Group Guidelines & Question 1 – 35 minutes

KARI – Brief overview of group guidelines

### SMALL GROUP FACILITATION – QUESTION 1

In each group, each person will take 5 minutes to tell a story about a time they tried to advocate for themselves/accessing certain services within academic, health, or mental health support services at the University of Victoria and it did **not** go well. Think about the details of what happened before, during, and after the event, as well as what you were thinking and feeling as the event unfolded.

1. Once the person is finished sharing their story, each person in the group will go around and share one thing that stuck out to them – it could be a reaction to hearing the story, a quality of the person you noticed, or a barrier that you noticed arising for the person.

\*\*Someone may share their story very quickly or need help with questions to share more details. Ideas for follow-up questions:

- What was your reaction to this experience?
- Did this experience impact your thoughts or decisions going forward?
- Probe them on the whole story, people involved, emotional reactions

### Part 3: Small Group Facilitation Question 2 – 30 minutes

, in each group, each person will take 5 minutes to tell a story about a time they tried to advocate for themselves within academic, health, or mental health support services at the University of Victoria and it **did** go well. Think about the details of what happened before, during, and after the event, as well as what you were thinking and feeling as the event unfolded. If you cannot think of a time that did go well, you could also tell a story of what your ideal situation or story would be when trying to navigate support services at the University of Victoria.

1. Once the person is finished sharing their story, each person in the group will go around and share one thing that stuck out to them – it could be a reaction to hearing the story, a quality of the person you noticed, or a barrier that you noticed arising for the person.

## Part 4: Small Group Facilitation Question 3 – 30 minutes

In small groups, reflect on what's been discussed here today, and especially the role of advocacy and self-advocacy.

- 1. From sharing your story and hearing others, in what way could advocates be helpful for students?
- 2. When you look at your own drawing from the start of this workshop, do you notice any patterns in what was helpful or not helpful?

Follow up: When you're thinking of the different people that you ran into, is there anyone that made a significant impact on looking for resources, whether that was good or bad?

### **Part 5: Self-Reflection and Closing**

KARI - Participant quiet reflection time: What's most stood out from our conversation today? What do you most wish others could learn from what we've talked about today? What was there not time to talk about today that is important? (~10 minutes)

KARI – Closing, gratitude, contact info and supports information

#### Session 2

Note: Session 2 is intended to be much more FLEXIBLE and OPEN-ENDED than Session 1. Your role in facilitation is even moreso just to ask the questions and let the group discuss. Your main job will be to jump in if some folks aren't getting a turn to share, re-direct if the group gets off topic, or ask follow-up questions if the conversation lulls.

#### Overall schedule:

1:00 – Introduction including key definitions (e.g., advocacy, navigation), our goals for a final product, and review of consent and group guidelines (10 minutes)

AND first group question (30 minutes)

- 1:40 break
- 1:50 Second group question
- 2:10 break
- 2:20 Third group question
- 2:50 break
- 3:00 Fourth group question
- 3:30 break
- 3:40 Self-reflection time and wrap up

## Part 1: Introduction and Key Definitions – 10 minutes Small Group Facilitation Question 1 – 30 minutes

KARI – Welcome and gratitude, discussion of our goals and key definitions for today, review of consent and group guidelines

### SMALL GROUP FACILITATION - QUESTION 1

Open with the first of these questions, and then you can ask as many or as few of the follow-up questions as your group needs to keep exploring this question.

Initial question: What could this group create in the short-term to help future students advocate for themselves (or each other) at university?

### Follow-up:

- What would you really not want to see?
- What resource would you have loved to have had when you started your self-advocacy?
- What types of resources exist that are helpful but could be enhanced or could be better?
- Does anyone have any ideas that are different than what we've discussed so far?

### **Part 2: Small Group Facilitation Question 2 – 20 minutes**

In the previous question we talked about what we could create in an advocacy resource. In an ideal world, how would people be able to access this resource?

### Follow-up:

- If people are being vague, ask for specifics of when/where/how this resource should exist
- Thinking about things you've tried to access in the past, what made it easy to access and what made it difficult to access?
- Is there a resource you haven't accessed because there's been some type of barrier to accessing it?
- When have you most needed to access resources?
- Does anyone have any ideas that are different than what we've discussed so far?

#### Part 3: Small Group Facilitation Question 3 – 30 minutes

What's worked well for you when accessing resources/supports or advocating for yourself at UVic?

#### Follow-up:

- What specific steps would you advise people to go through (within specific services like CAL, Counselling, with professors)?
- Is there any way that you interacted with the specific person that helped you interact with the services (e.g., polite, assertiveness) that helped your outcome?
- What supports you to be able to advocate for yourself (e.g., personal qualities, relationships, other services)?

### Part 4: Small Group Facilitation Question 4 – 30 minutes

What would make self-advocacy at the university easier?

Or, rather than helping students self-advocate, what other types of changes may support students to not *need* to advocate for themselves as much? (This is looking more at LONGER TERM change)

## Follow-up:

- Ask about specific areas (e.g., self-advocacy within Student Wellness, CAL, with professors and programs)

### Part 5: Self-Reflection and Wrap-up

Participant quiet reflection time: What's most stood out from our conversation today? What do you most wish others could learn from what we've talked about today? What was there not time to talk about today that is important? (~10 minutes)

KARI – Closing, gratitude, contact info and supports information