UNHEARD VOICES OF INDIVIDUALS WITH NEURODEVELOPMENTAL DISABILITIES: NAVIGATING MENTAL HEALTH CHALLENGES

by

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Bachelor of Arts, Kwantlen Polytechnic University, 2016

Thesis
Submitted in Partial Fulfillment of the Requirements for
the Degree of

MASTER OF ARTS IN COUNSELLING PSYCHOLOGY

in the

FACULTY OF GRADUATE STUDIES

TRINITY WESTERN UNIVERSITY

May 2024

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ACKNOWLEDGEMENTS

This project began with noticing a need and feeling compelled to do something. I want to take a moment to express my heartfelt gratitude to those who recognized my passion and enthusiasm and encouraged me along the way.

Thank you to Dr. Marvin MacDonald for his unwavering support and encouragement throughout the thesis process. Your insightful questions, curiosity, and inspiration have propelled this project beyond my expectations.

Thank you to Estera Boldut for your leadership in this field; your expertise has been invaluable. Dr. Rachelle Hole, thank you for your thoughtful questions and consideration. Your work continues to inspire me.

Growing up in an environment where disability was not seen as a limitation shaped my perspective significantly. For that, I thank my brother Kent, whose joy, resilience, and kindness have profoundly influenced my life. I am also deeply grateful to my mom and brother Lunden. Together, we form a small but mighty family unit.

Lastly, but most importantly, I extend my deepest appreciation to my husband, Daniel. Your steadfast support has allowed me to pursue my dreams. To my children, Cadence and Levi, may you always know never to limit your dreams

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ABSTRACT

There is significant evidence that individuals with intellectual and developmental disabilities (IDD) have more traumatic life experiences than those without a disability. Research has also highlighted that people with higher levels of traumatic events throughout their lives are more likely to receive a mental health diagnosis. However, adults with IDD who experience mental health diagnoses are rarely given the same therapeutic opportunities as someone without a disability to process experiences that may impact their mental health. This project inquired about the lived experience of those with an IDD in living with mental health symptomology. The project also addresses the systemic barriers individuals with IDD face when seeking out mental health support, the importance of a strong support network, and the distinct lack of knowledge about mental health among individuals with IDD. The results highlighted the need for increased trauma-informed and plain language resources for individuals with IDD.

Key Words: Developmental Disability, Autism, Mental Health, Counselling, Trauma

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CHAPTER 1: INTRODUCTION

Imagine you woke up one morning, and your voice no longer mattered. Your view of yourself and your needs was no longer deemed important. Instead, when someone wanted to know something about you, they did not talk directly to you, they spoke to your parent or caregiver. Now also imagine you were having a tough time with your mental health. You may be experiencing symptoms of depression, anxiety, or panic. You were aware of your thoughts and feelings, however, they were not considered when deciding how to support you with your symptoms. Instead, your symptomology was questioned, and if it hit a certain number of boxes, you may be diagnosed with a mental health disorder and likely prescribed medication. Due to many factors, you may also not know how to communicate your needs clearly, so when you were experiencing mental health symptoms, you had outbursts that impacted your ability to be part of the community. So, a behavioural interventionist supports you in changing the behaviour rather than asking if you are having a challenging time and need to speak to a mental health professional. This scenario describes what is often the experience of those with disabilities and neurodiversity when they experience mental health symptoms.

First, let me acknowledge how far disability rights and movements have come. Advocacy groups, lawmakers, and families have done phenomenal work ensuring everyone has access to health services and support within Canada. Additionally, those who support individuals with disabilities and neurodiversity tirelessly strive to ensure their well-being and quality of life. Unfortunately, these stakeholders are often working in a broken system that rarely offers holistic approaches to mental health services (McNally et al., 2021).

Furthermore, most would agree that diversity and inclusion are beautiful things. Anecdotally, many would argue for inclusion, fair treatment, and justice for all people. However, when it comes to the realities of the disparities of treatment between those who are neurodiverse and have disabilities and those who are not, there is often a disconnect on how and why these things matter. There is also a constant disagreement within professional and policy communities on the capacity of those who are neurodiverse to understand their own experiences. (McNally et al., 2021).

For clarity, it is essential to define terminology at the very beginning. There is often debate surrounding the definitions and classifications of disabilities and neurodiversity. In Canada, both individuals with developmental and intellectual disabilities, as well as those who are neurodivergent, are technically classified as having a neurodevelopmental disability as per the Diagnostic and Statistics Manual of Mental Disorders, Text Revision (DSM-5-TR) (American Psychiatric Association, 2022). In many parts of Canada, the term intellectual and developmental disability (IDD) is used to designate developmental disabilities, neurodiversity, such as autism spectrum disorder, and many other disorders, such as fetal alcohol syndrome (Keesler et al., 2023). For this paper, I also use the term IDD when referring to the literature and participants in this study. A clear definition is also given in the glossary of this paper. However, no adequate single term is sufficient because each person is unique, and some people may prefer different wording. Therefore, when I spoke with participants, preferences were discussed at the beginning of each interview to ensure their preferred terms were utilized throughout the research process.

Personal Connection

I grew up with an understanding that all humans are worthy of dignity and respect. My eldest brother, Kent, lived with significant IDDs and physical disabilities. As a result, I had a lifetime front-row seat to see how people speak to or about individuals who cannot advocate for themselves. On many occasions, when with my brother, someone who did not know us would only speak directly to me while not even acknowledging Kent, even if the discussion was about him. This exclusionary practice was my introduction to people not understanding the capacity of people with IDDs to understand and their ability to interact.

For the last 15 years, I have worked with adults with IDDs in various capacities. Throughout this time, I have had the honour and privilege of supporting people in pursuing their dreams and goals from a person-centred framework. On multiple occasions in calm moments with individuals I supported who had challenging behaviours, conversations often touched on not being happy about specific elements of their lives, underlying factors of lack of control in their lives, memories that come up of someone being unkind to them in their life, or past abuse and assault. These memories often took over in heated moments and, at times, would result in those being supported lashing out at those around them. I have always wondered if we can support individuals with IDD to process those experiences therapeutically. Can expanding one’s tolerance of uncomfortable emotions increase respect for their history and story? Can therapeutic processing of stresses and traumas decrease aggressive behaviour? However, a very real challenge is that counselling services are rarely funded for those with an IDD. Even with funding in place, finding a therapist who possesses both foundational knowledge and a deep understanding of the complexities faced by individuals with IDDs has remained a significant challenge.

The Study

Through my experience working in direct support of individuals with IDD and my knowledge through reading and research, I have come to understand that individuals with IDD disproportionately experience adverse life events and traumatic events throughout their lifetime

(Cook & Hole, 2021; McNally et al., 2021; Tint et al., 2023). Research has shown that starting from early childhood and moving into adulthood, individuals with IDD experience significant levels of abuse, neglect, bullying, and lack of autonomy (Kildahl et al., 2020; McNally et al., 2021; Tint et al., 2023). Research has also clarified that individuals with IDD react and respond to trauma in a similar way as someone without a disability would (Kildahl et al., 2020; Wigham et al., 2011). Additionally, empirical evidence has shown that adverse and traumatic events negatively impact a person's mental health (Wigham et al., 2011). This pattern has been found in both disability and non-disability research (Wigham et al., 2011). However, individuals with IDD are less likely to receive support related to these events (Olsen et al., 2017). This gap may be due to a lack of available resources, service level barriers, or other sources of neglect.

This background understanding leads to the following research questions, which are as follows. What is the lived experience of those with an IDD who are self-advocates who have experienced mental health symptomology? What was their experience in gaining access to and receiving mental health support in British Columbia (BC)?

This study looks at the first-hand experiences of individuals with IDD experiencing mental health symptomology. There are some international research studies on these topics. However, most utilize a caregiver to speak on behalf of the individuals' experiences. In this study, I interview the individuals directly and listen to their stories and accounts. To accommodate this approach, those who participated needed to be able to advocate for themselves, a status known as being a self-advocate. A self-advocate is a person who can articulate their needs and make informed decisions about the support necessary to meet those needs (Ellem et al., 2022). While participants did not need to be able to make independent decisions for every mental health concern or service, they did need to have the capacity to speak to their lived experiences. Through the interviews, the line of questioning focused on their view of self as self-advocates, their experiences when having mental health symptoms, the type of support they received, and how they are doing now. Time was taken to understand each participant's story and experiences that may have impacted them.

Furthermore, this study takes a holistic view of the individual. Often, individuals with IDD are treated for their symptoms rather than investigating the cause(s) of their pain; taking a holistic approach to understand individuals with IDD as deserving of support propelled this research. This slant highlights the importance of seeing those with IDD as people who require the same mental health support and access as those without a disability or neurodiverse history. Regarding support, I will look at not just medical interventions but natural supports around the individual that may be helpful during that time.

Critical disability theory (CDT), in connection with self-advocacy, heavily advocates for the voices of people with IDD to be heard. CTD is rooted in the understanding that disability is not just a medical condition but a socially constructed phenomenon developed by ongoing power dynamics and societal norms (Arstein-Kerslake & Black, 2020). Joining CDT and self-advocacy created the foundation of this research project, which informed the framework of this thesis project. See glossary for further definitions.

Critical Disability Theory

Disability theory has been around for decades and has gone through multiple phases and transitions. In the 1970s, disability rights movements began to make headway. At the core, they were arguing for the same basic civil and political rights for individuals with IDD as any other citizen had (Arstein-Kerslake & Black, 2020). Simultaneously, disability studies gained traction, with the aim of understanding what factors led to the social, political, economic, and structural exclusion of those with IDD (Arstein-Kerslake & Black, 2020). For a long time and in some areas, to this day, a medical model of disability has often been used. This model views individuals with IDD as people who need to be treated medically for their disability to be cured (Arstein-Kerslake & Black, 2020). Moreover, the medical model views disability as a biological condition that negatively impacts the individual and, therefore, needs to be fixed (Wieseler, 2018). Next came the social model of disability, which shifted the focus from the biological impairment to the societal oppression a person may experience due to their disability (Wieseler, 2018).

In response to the above models, CDT emerged. At the core of CDT, one looks at developing solutions to the structural, economic, and cultural exclusion of individuals with IDD (Arstein-Kerslake & Black, 2020). CDT argues that all individuals deserve respect and dignity regardless of ability. However, due to societal ideals, many individuals are discriminated against. CDT insists that we must question and challenge how we view disability and equality with our current view, full equality would not be possible (Rioux & Valentine, 2006). Instead, we must unlearn the narratives surrounding disability and view individuals with IDD as fully human and able to participate in society (Rioux & Valentine, 2006). This paper will take a CDT lens, viewing all aspects of the project from this framework.

CHAPTER 2: LITERATURE REVIEW

Research in disabilities is vast and each new era has extensive literature written about topics that become centres of attention. This study focuses on three main areas. First, I look at a strengths-based focus, highlighting different views that have been utilized and how support was organized for individuals with IDD. I emphasize the current support offerings that are provided for individuals. Next, I address diversity across all people and how I often only see and learn about a small portion of the population. Through that overview, I narrow our focus to individuals with IDD. I also discuss the negative impacts of diagnostic overshadowing and how this has consistently and negatively impacted individuals with IDD. Finally, I highlight research regarding adverse life experiences and traumatic events that can lead to mental health problems later in life. These research findings guide professionals to focus on more holistic support for individuals with IDD and can help explain the history and why holistic support may not be offered.

Current Systems for IDD Support

Strengths-Based Systems and Critical Disability Theory

Historically, a deficit-based approach was taken when assessing services for people with IDDs. The focus of support has been on what individuals with IDD cannot do, areas they may struggle in, and what others without disabilities can do to come in and fix their situation. However, in many social service agencies, professionals and advocates are arguing for a strengths-based focus to replace deficit models. A strengths-based focus reframes the deficit-based model by valuing the empowerment of individuals seeking support. Additionally, this focus advocates for a collaborative relationship rather than one of authority over individuals needing support (Caiels et al., 2021). A strengths focus also emphasizes prevention, and so reduces costs of human suffering and remedial services. The main priorities of a strengths based focus are understanding the strengths of an individual and moving away from a pathological or biological illness model, also see glossary for additional definitions (Caiels et al., 2021).

Some arguments against a strengths-based focus surround the risk that this view will not account for people's realities. Stating that the realities of those accessing social services are challenging and complex, focusing solely on one's strengths may put a “silver lining” or “self-help” perspective on people's needs (Caiels et al., 2021). While it is important to be aware of and cautious about such possibilities, it is equally crucial for all support to be collaborative and to focus on what individuals can do and accomplish as part of the overall care plan. Other arguments supporting a deficit approach focus on the balance between empowerment and disempowerment, and the newness of this view means there is not much research on the effectiveness of this model (Caiels et al., 2021). However, both of those arguments have been challenged by re-emphasizing the need for collaboration and deployment of both deficits’ identification and strengths recognition in all social services.

CDT identifies a strengths-based approach as essential. CDT argues that many of the situations that individuals with IDD are in are due to societal structures, medical model preconceptions, and deficit-based approaches. Historical models position the person with an IDD as the victim, one in need, or disempowered. However, CDT and a strengths-based focus highlight each human’s strengths and resiliency. This model demands that those who offer support acknowledge that the client/practitioner relationships must be equal (Moore, 2022). Moore (2022) states that social support workers must be “willing to meet them eye-to-eye and engage in dialogue and mutual sharing of knowledge, tools, concerns, aspirations, and respect” (p. 453). Moore also argues that keeping the view of individuals with IDD as it is today takes away their ability to advocate for themselves, to have a say in their lives, and to move toward the change needed to move the power to the person supported. At the core, this lens focuses on collaboration and mutually exploring personal and community resources.

Current Mental Health Support for Individuals with IDD in BC

As we shift to a strengths-based approach, it is vital to examine the dominant interventions offered for individuals with IDD who may also be experiencing mental health symptoms. As well as touch on a brief history of how these services developed. Specifically, within BC, the last institution for individuals with IDD closed in 1997, only 26 years ago (Tang et al., 2008). While this was a triumphant win for the disability community, agencies within the community were not prepared to support the influx of individuals who were no longer supported by institutions. Since then, community and government agencies have been trying to catch up to the needs of individuals with IDDs (Tang et al., 2008). Currently, there are no acute mental health crisis resources for individuals with IDD outside of the usual emergency and inpatient psychiatric units in BC. Historically, those with IDD have done poorly in traditional psychiatric settings due to their complex needs and staff without training in the best ways to support individuals with IDD (Tang et al., 2008). The only publicly funded facility support in BC is a provincial assessment centre; however, this is typically only utilized in extreme cases where individuals are a threat to themselves and/or others.

For individuals who have mental health symptoms that do not require emergency services, Community Living British Columbia (CLBC) makes a referral to Developmental Disability Mental Health Services (DDMH) through regional health authorities such as Fraser or Coastal Health. When this referral is made, the individual waits to see a psychologist, which can vary from a few weeks to several months. Then, through a basic interview with the individual and their support network, the psychologist will decide if the individual has a mental health disorder. If diagnosed, medication will likely be prescribed to minimize symptomology, and periodic check-ins will take place until the client is stable. If not, the individual does not receive any publicly funded professional support. Throughout that process, if the individual displays any behavioural problems that limit their ability to engage in the community, they will likely be referred to a behavioural interventionist to create a plan to begin modifying problematic behaviour. The regional health authorities' websites note that counselling is offered, however, research has highlighted that this often does not occur due to the extreme lack of clinicians with training and expertise in IDD (see Fraser Health, n.d.; cf. Tang et al., 2008). Additionally, there is very limited specialized support that has been made available for this population and little education is provided for practitioners, which continues to lead to a lack of understanding of the individuals supported. These gaps then continue to propel inaccurate narratives around individuals with IDD and their abilities.

While many advocacy and community living agencies are fighting for a strengths-based model to be used, a massive institutional hurdle is that these services are still being offered within a medical-model system. Additionally, many individuals with IDDs rely on CLBC to provide funding for mental health services. This is challenging because even if a person meets all the criteria as per the DSM-5 TR for a diagnosis and sees a psychologist to be officially diagnosed, that does not guarantee additional funding or support. Unfortunately, CLBC rarely provides funding for sufficient support and services that would benefit the individual seeking mental health services since their focus is on controlling costs. So even when individuals with IDD check all the boxes diagnostically, CLBC can still decide if their needs are within budget constraints.

Support Networks

Support networks are the people in a person's life who support a person in their daily life to fulfil their dreams and goals and who help them when they may be struggling. A support network may be one or two people, or it could be a whole community that surrounds a person and looks out for their needs. With or without a disability, most people have some sort of support network around them. However, many individuals with IDD are more reliant on their support networks in their adult lives (Sanderson & Aquino, 2023). Those who consider themselves self-advocates, who are more independent, often have a strong support network around them. This support network teaches them about advocacy and life skills for independence as well as a safety net for them as needed (Sanderson & Aquino, 2023).

For many individuals with IDD, their primary support network is their families. This is often referred to as a person’s natural support (Sanderson & Aquino, 2023). Often, the needs of a person with an IDD become greater than what the family can provide independently. Also, many individuals with IDD rightfully want connections outside of the family home. The most common way this is done is through agency programs and services, which are sometimes referred to as formal supports (Reynolds et al., 2018). Together, a person’s natural and formal support creates their support network, please refer to the glossary for further definitions (Reynolds et al., 2018).

What is now clear is that a person’s support network is incredibly important to their overall well-being and the support that they receive (Reynolds et al., 2018). Many individuals with IDD do not receive adequate formal support that takes care of all their priority needs. For many, their natural support network is often responsible for taking care of the rest and they are put in a position where they need to advocate for better services for the individual with an IDD

(Reynolds et al., 2018). Unfortunately, adequate support is rarely provided without heavy advocacy from a personal support network.

Many support systems are responsible for the well-being of the individual they are supporting with minimal options for help (Reynolds et al., 2018). Specifically, when the family system is typically seemingly doing well, often little formal support is offered, even in a crisis. When adding the complexity of mental health symptomology into the family, it is often the natural support network that is required to step up again. This often involves them identifying the need for greater support and then finding those supports, which are often privately funded. While being a support person is meaningful, it can also be incredibly challenging when working within a system that often does not provide adequate help (Lunsky et al., 2014). With the addition of long wait lists, not enough services, and a person with complex needs, much of this unspoken responsibility falls to the support network.

Diversity & Intersectionality

By discussing disability rights, we are inherently discussing human rights. In mainstream North American culture, entertainment media often feeds us a version of normal or admirable that fits consumer perceptions, specifically reflecting pre-existing beliefs regarding those with disabilities (Mustafja & Din Cin, 2023). In reality, humanity is beautifully diverse and complex. When we look at the world around us, rarely do we think about what is shown in ads, mass media, or educational settings. However, when we take a closer look into Canadian systems, a Eurocentric point of view is often exaggerated, and stereotypes of other groups are often assumed. Whether it is implicit or explicit, most of us hold some assumptions or ideas about disability (Cocq & Ljuslinder, 2020; Dungs et al., 2020). The lack of disability shown in a positive or strengths-based way, has drastically impacted how many individuals with IDD are viewed across the board (Basselin, 2020, p.3; Cocq & Ljuslinder, 2020).

Information about people is often given in ways that appear objective, however, unspoken societal rules are often laced throughout, often excluding those who do not fit into mainstream ideals (Dungs et al., 2020). As a society, Canadians have moved towards inclusion, but not necessarily towards acceptance and welcoming into mainstream society (Dungs et al., 2020). To navigate conventional society, typically, individuals with IDD must prove that they are normal enough to fit in (Konrad, 2021). This dynamic of camouflage can create access fatigue, where to receive minimal acceptance, individuals must vulnerably present themselves (Konrad, 2021). Konran continues that access fatigue can result in physical and mental exhaustion from the work and effort it takes to educate others about their needs to have access to services. Due to this awkward balance and clear exclusion, many views of individuals with IDD are simply not seen or shown (Konrad, 2021).

There is a wide spectrum of individuals with IDD, with all of them having distinct characteristics, attributes, and needs. Like all people, individuals with IDD come with a wide variety of life experiences, strengths, skills, and knowledge. Nonetheless, due to the historical dominance of deficit-based models, it has often been assumed that those with IDD are in constant need of help. Of course, mass media has certainly not helped with this narrative, with them predominantly portraying disabled individuals as unaware or childish outcasts. However, as those with disabilities emerge and fight for their seats at the table, it comes with resounding evidence that many are incredibly intelligent and capable, able to advocate for themselves and others and have more strength and resiliency than has been usually imagined. However, despite significant progress, current healthcare systems continue to make it challenging for professionals to recognize the ability of individuals with IDDs to self-advocate.

Additionally, many individuals with IDD face increased intersectionality of discrimination. This often happens due to the marginalization of specific social classes, ethnicities, or genders (Cocq & Ljuslinder, 2020). When a person with an IDD comes from a diverse background, this can compound the discrimination and lack of understanding they may receive. Further, when a person with IDD is then diagnosed with a mental health disorder, this intersectionality of challenging access continues to compound. Appendix B highlights a visual that encapsulates the complexity of intersectionality and the layers of impact in a person’s life.

Diagnostic Overshadowing

Within the medical field, the lack of understanding and education surrounding individuals with IDD has been detrimental. This problem is so prevalent that a term was coined to highlight a phenomenon that has been happening. Diagnostic overshadowing describes situations where an individual with an IDD seeks medical or mental health support, and their practitioner blames all their symptoms on their disability rather than recognizing the problem for which they are seeking help (Kildahl et al., 2020; Mason & Scior, 2004). This problem is often rooted in bias and discrimination and can be so harmful that it is considered a life-changing event that has the chance to be catastrophic (Gardner, 2023). Many individuals with IDD seek mental health support and are met with unhelpful answers that put the blame back on them and their IDD. Additionally, if one receives mental health support and has an IDD diagnosis, they now have a compound chance of physical symptoms being overlooked (Molloy et al., 2020).

Education and advocacy are the primary ways to combat diagnostic overshadowing (Gardner, 2023). As with all other disability movements, understanding systemic oppression is imperative to creating change. This not only needs to happen within mainstream society but also within the medical field. Understanding this connection is crucial in providing comprehensive and fair healthcare, as it asks that healthcare practitioners look beyond the surface and consider the broader life experiences of individuals with disabilities, ensuring that trauma and adverse life events are not overshadowed or left unaddressed in their care and support.

Adverse Life Events and Mental Health

There is consistent and compelling evidence that starting from childhood, individuals with IDD experience more adverse and traumatic life events than those without disabilities (Cook & Hole, 2021; Hastings et al., 2004; Hatton, 2002; McNally et al., 2021; Rittmannsberger et al., 2020; Wigham et al., 2011). These events are noted in many areas, including physical, sexual, and mental abuse, exclusion, use of physical restraints, bullying, less access to education and health services, and lack of autonomy within their lives (Cook & Hole, 2021). Evidence also highlights that those with IDD respond similarly to trauma and adversity as do those without a disability (Wigham et al., 2011). It has been demonstrated that many people with an IDD who have experienced traumatic events are likely to experience a mental health disorder in their lifetime (Hastings et al., 2004; Rittmannsberger et al., 2020; Wigham et al., 2011).

Evidence also highlights that mental health disorders in this population increase challenging behaviours (Hatton, 2002; Rittmannsberger et al., 2020). Challenging behaviour is one that may cause harm to the individual or another person or that impacts their ability to be in the community (Rittmannsberger et al., 2020). This connection may reflect emotional dysregulation after an adverse or traumatic life event (Rittmannsberger et al., 2020). An individual may be suffering from PTSD and not have the functioning to express that distress without support (McNally et al., 2021). More specifically, individuals with IDD are rarely taught to discuss their feelings and experiences; however, research has shown that trauma has a significant impact on the human brain and will eventually make its impacts known (Hastings et al., 2004). Other articles suggest that for many people with IDD, the symptoms of trauma may be more subtle, including reactions such as withdrawing, decreasing speech, or behavioural regression, which can make it easy to miss the signs of trauma (Kildahl et al., 2020).

While there has been a significant increase in research on trauma over the last 40 years, minimal amounts have been focused on individuals with IDD (McNally et al., 2021). This neglect has increased the gap in knowledge surrounding the impacts of trauma on individuals with IDD (Cook & Hole, 2021). However, it has been found that people with IDD experience the same mental and social impacts of trauma as those without disabilities (McNally et al., 2021). Through a meta-analysis, it was highlighted that we must be aware of the social realities of many individuals, such as systemic oppression, discrimination, and lack of opportunities and resources that may compound the impact on one's ability to access mental health support (McNally et al., 2021). Additionally, their review found that individuals with IDD are much less likely to be offered and treated therapeutically for their traumatic experiences and symptoms (McNally et al., 2021).

A complexity is that most clinicians are not trained in working with individuals with IDD. Several studies mentioned having to make adaptations to assessments, watch for different markers, and move at the individuals' pace to adequately understand the extent of their mental health functioning (Cook & Hole, 2022; Hatton, 2002; Kildahl et al., 2020; McNally et al., 2021). There is an added barrier in all these situations if clinicians do not know what distinctive markers to look for since they may miss symptoms or fall prey to diagnostic overshadowing (Kildahl et al., 2020). This brings us back to our discussion of frameworks surrounding disability and why it is important to acknowledge systemic oppression. Medical models of “fixing” and lack of knowledge about individuals with IDD within the healthcare system continue to perpetuate oppression and discrimination regardless of intention. Utilizing CDT and a Strengths-Based focus allows individuals with IDD to be seen as fully human, requiring the same support and understanding as anyone else. There must be a continued transformation in how society views individuals with IDD to have lasting change.

To tie it together, individuals with IDDs are disproportionately exposed to traumatic and adverse life events (Cook & Hole, 2021; Hastings et al., 2004; Hatton, 2002; McNally et al., 2021; Rittmannsberger et al., 2020; Wigham et al., 2011). Research indicates that individuals with IDD are similarly affected by trauma as those without disabilities, often resulting in mental health disorders that can increase challenging behaviours (Wigham et al., 2011). While the impact of trauma on individuals with IDD has been underexplored in research, it is clear they face similar mental and social consequences as the general population. These effects of trauma are then compounded by systemic oppression, discrimination, and limited access to mental health support. The limited training among clinicians in working with individuals with IDD further complicates matters, often leading to diagnostic overshadowing and missed opportunities for therapeutic intervention (Kildahl et al., 2020). To address these challenges, it is important to adopt frameworks such as Critical Disability Theory (CDT) and a Strengths-Based approach, recognizing the humanity of individuals with IDD and advocating for their equal access to appropriate support and mental health services. This shift in societal perception is essential for meaningful and lasting change in the lives of individuals with IDD.

Trauma-Informed Practices

Trauma-informed care is an approach that takes into consideration and responds to the prevalence and consistent impact of trauma through policies and practices that are informed by the important aspects of safety, choice, collaboration, empowerment, and trustworthiness (Keesler et al., 2023). Please reference glossary for further definitions. This approach emphasizes the physical, psychological and emotional well-being of those who have experienced trauma and supports a person to rebuild a sense of control in their lives (Williamson & Qureshi, 2015). A standard outline of this type of care often looks at the four Rs for a framework: Realizing the widespread impact of trauma, Recognizing the signs and symptoms of trauma, Responding by implementing knowledge about trauma into practice, and Resisting re-traumatization (Keesler et al., 2023). Even with increased popularity, disability services have been slow to adopt a trauma-informed approach to support, even with the evidence of increased trauma in the lives of those who live with IDD. As we assess the needs of those with an IDD while taking into consideration the traumatic life events many individuals face, trauma-informed care is an imperative step to increase the overall well-being of those with IDD.

Integrative Summary

The research questions for this study focus on the lived experience of individuals with IDD’s when experiencing mental health challenges. Through the literature review, I have highlighted some important factors that contribute to the question as well as why it is so important to gather first-hand experiences. Throughout the last 40 years, individuals with IDD have been advocating to have a voice in their own care and circumstances. While the disability field has advanced in some ways, many individuals still do not have the opportunity to communicate their needs. Throughout the framework of this project, the objective is to amplify these first-hand experiences as much as possible.

Furthermore, the resiliency and strength of individuals with IDD are profound. Highlighting these strengths is the foundation on which the project rests. Additionally, Critical Disability Theory helps us understand that systems of oppression intentionally built around this group exist. How we view individuals with IDD drastically impacts how services are funded, offered, and designed. If we continue to see this population through a deficit-based lens, then support and services will remain incomplete.

Finally, the statistics around trauma, adverse life events, and their impacts show us challenging, real complexities (Cook & Hole, 2021; Hastings et al., 2004; Hatton, 2002; McNally et al., 2021; Rittmannsberger et al., 2020; Wigham et al., 2011). The painful realities that many with IDD have faced are devastating. Looking forward~~,~~ through a strengths-based and trauma-informed lens, this group also deserves the same access to mental health support as those who do not have IDDs. There needs to be a change in the systems that offer only band-aid fixes to real mental health problems. This project focuses on first-hand experiences as crucial resources for supporting advocacy for equal access to mental health services.

CHAPTER 3: METHODS

This methods chapter highlights the paradigm that influenced this study's design and methodology. I outline the chosen method of research, how and why this was selected, and my approach to data analysis. I also highlight whom the study looks at, ethical considerations, data collection, and other protocols. This section gives a detailed outline of the boundaries in which the project takes place, highlighting the vital principles of flexibility and adaptability in conducting a project that encourages the participants to contribute equal say and input.

Transformative Paradigm

The paradigm influencing this study and all its decisions is a transformative paradigm. The transformative paradigm openly acknowledges the social and cultural power structures that have contributed to unequal access and opportunities for certain groups of people (Jackson et al., 2017). When applied to the research context, it can be understood that participants must be at the centre of the research, always highlighting the importance of their experiences and identity (Mertens, 2021). There must be a focus on addressing the high levels of social, cultural, and economic injustice participants face (Mertens, 2021). However, it is not sufficient to acknowledge the inequality. Research, when coming from a transformative paradigm, must be action orientated. This requires the researcher to set out to increase justice whenever possible (Phelps, 2021).

This lens also amplifies the stories and experiences of those who are marginalized while highlighting their resiliency and strengths (Phelps, 2021). Too often, marginalized groups are highlighted as weak or needy. When holding a transformative paradigm, it is imperative to focus on the inherent strengths of a population. Additionally, it is important to highlight those strengths throughout the research and to bring them to the forefront of every study. This works to highlight a population's strengths when they are often seen otherwise and to invite collaboration with those who are the subject of research by seeing them as equals.

Transformative Paradigm in Action

As already established, this study focuses on the lived experiences of individuals with IDDs. As previously documented in the literature review, individuals with IDD have experienced vast amounts of discrimination from society. Further, increased adverse life events, such as abuse, neglect and exclusion, only compound their negative experiences. With the transformative paradigm maintaining that we must acknowledge the harm social and cultural power systems have inflicted on marginalized populations, this paradigm appears to be a natural fit for my study. Therefore, through this project, we brought attention to systemic oppression while focusing on the strength and resiliency of individuals with IDD. Remembering all this population has done to fight for their seat at the table has been essential.

The transformative paradigm also directly addresses the challenging positions of those with IDD. Mertens (2019) highlights how the transformative paradigm aligns with disability theory. Since previous medical and biological models have focused on this group's deficits, a transformative paradigm shifts the focus to a strengths-based model. Additionally, there has been a massive shift in bringing power to individuals with IDD (Mertens, 2019). The disability community's activities often state, “nothing about us without us,” highlighting the need to move the control to the hands of those with IDD (Mertens, 2019, p. 26). In this, Sullivan argues that “it is time that those with IDD walk side by side with the nondisabled in all research about them and as we move toward social justice” (Sullivan, 2009).

Through the transformative paradigm, the researcher must take seriously the implications of their research. For example, the researcher needs to consider how asking the research question(s) will impact the marginalized community or subject being researched. Additionally, it is important to note the importance of ethical considerations beyond the research project and publications (Phelps, 2021). Phelps (2021) acknowledges that adopting an action or participatory focus, there is an expectation that researchers will translate their findings into meaningful actions that improve the lives of those who were involved. This project focuses solely on individuals with IDD, often a marginalized population within society, and their experiences with a sensitive topic, mental health. With the results, the goal is to advocate for more resources and funding for individuals with IDD to receive trauma-informed counselling support and services. This research also promotes further research to advocate for counsellors to become trained in working with individuals with IDD. Additionally, there needs to be increased funding for trauma-informed training for the support networks of individuals with IDD. Funders and educators will be pushed to increase funding and resources for this population when there is an established need.

Narrative Inquiry

With that pragmatic understanding, the project's structure draws on a narrative inquiry. This method was intentionally selected to highlight individuals with IDD experiences and stories. Ultimately, the main aim of narrative inquiry is to tell a story (Holley & Colyar, 2009). This method also allows flexibility in understanding the unique aspects of everyone’s story, allowing time and space for exploring their experiences. It also opens the door for partnership and enables the participant's voices to shine throughout the project (Josselson & Lieblich, 2003). A narrative is linked through each story, and meaningful events are highlighted to tell an overarching story that allows the reader to see the importance and impact of what is being described (Holley & Colyar, 2009).

The narrative inquiry also has a distinct ability to empower people to tell their stories and rewrite their narratives (Livholts & Tamboukou, 2015). Many individuals with IDDs have not had the opportunity to share their stories and experiences because their voices have been silenced. Through a narrative inquiry, participants' voices are amplified and at the forefront of the project. This allows the participants to share their experiences openly and honestly. Through this process, emerging themes and stories were highlighted. Participants' experiences were taken as they have been told, which may differ from what mainstream society emphasizes (Livholts & Tamboukou, 2015). When partnered with the transformative paradigm, there is a unique opportunity to amplify the voices of individuals with IDD through their stories and experiences. Creating a project that emphasizes individuals with IDD authentic experiences allows experiences for a greater understanding and development in research for individuals with IDD.

The narrative inquiry also focuses on the beginning, middle, and end of each participant’s story (Riessman, 2007). The line of questioning for the research question focused on their everyday life and experiences before and after noticing mental health symptomology. As well as who was there to support them and what their experiences were like in asking for help. I also aimed to understand in detail their experiences in receiving mental health support and services. Finally, I made every effort to capture where the participants are today and their experiences in finding ways to cope with their mental health symptomology. Throughout this process, main themes or ideas emerged from the participant's stories, and space was left for that to happen organically (Holley & Colyar, 2009).

The narrative inquiry method left room for natural stories and ideas to emerge. Through this experience, it was imperative to bracket my personal experiences and beliefs in order to ensure my experiences are not impacting the research. Josselson and Lieblich (2003) highlight the importance of approaching all the information with naivete. With this stance, we can lay down our presumptions and assume the participant is the expert in their own story. Throughout, the priority was to honour and respect the participants experiences while bringing the narratives or themes forward.

Characteristics of Participants

In this study, all participants have been previously diagnosed with an intellectual developmental disability as defined by the DSM-5-TR. The DSM-5-TR defines an intellectual developmental disability as a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains (American Psychiatric Association, 2022). Specific criteria can be found under sections F70–F73 in the DSM-5-TR. Alternatively, individuals must be diagnosed with neurodiversity, such as autism spectrum disorder per the DSM-5-TR. This may include symptoms such as persistent deficits in social communication or social interaction across multiple contexts over a period of time (American Psychiatric Association, 2022). Specific criteria can be found under section F84.0 in the DSM-5-TR. Additionally, they must be functionally impacted by their autism to the level to receive support through British Columbia Community Living (CLBC). To qualify for CLBC services, you must have a diagnosed developmental disability or neurodiversity status and potentially complete additional assessments, which a psychologist verifies. However, as previously mentioned, it is up to CLBCs discretion on the amount of funding each person receives.

Additional inclusion criteria included experiencing symptomology of a mental health disorder such as an anxiety disorder as defined by section F41.1 in the DSM-5-TR, depressive disorder in section F33.0–F33.9 in the DSM-5-TR, and/or bipolar disorder in section F31.11–

F31.90 in the DSM-5-TR (American Psychiatric Association, 2022). All mental disorders must be in psychosis-remission for a substantial period of time. Participants must also have stability in functioning since the diagnosis. Stability creates time for participants to process their diagnosis, which may give them a stronger ability to reflect on their experience.

Another requirement was that the participant be a self-advocate. A self-advocate is a person who can articulate their needs and make informed decisions about the support necessary to meet their needs (Ellem et al., 2022). Self-advocates can rely on their support network to make decisions, but it is important that the participants feel empowered to think for themselves. These individuals may speak verbally and/or use other modes of communication. Still, it is essential for this study that individuals with IDD have the opportunity to communicate for themselves directly. All questions and materials are written in “plain language.” This means all questions for data gathering were written in their most straightforward possible format (St. John et al., 2022).

Exclusion criteria included interested participants wanting to complete the study; however, in the initial screening, they became emotionally dysregulated and likely would not be able to speak about their situation during interviews. The main reason for this exclusion is that participating may harm them. Additionally, while having someone advocate for and even accompany the supported individual is welcomed, the participant must be able to primarily communicate their experience rather than the support person speaking on their behalf. The main reason is that the study aims to have first-hand accounts, and we want to ensure that, in every way possible, that is what is collected.

Recruitment

Participants for the study were recruited by a snowball strategy where I contacted local community living organizations and provided information about the study. I also reached out to several local self-advocate groups that run independently of government-funded organizations to invite members to join the study. Additionally, I posted my study on social media such as Facebook, to spread the word and generate participants. I intentionally used purposive sampling to ensure that I reached a diverse demographic in responses. For example, I reached out to organizations beyond those with whom I have an existing relationship with. I created a poster ad to highlight the project and details and sent an initial email with basic information (See Appendix H).

After a participant showed interest, an intake interview was conducted to assess fit for the study (See Appendix F). These interviews took place via phone, zoom, and in person. During recruitment, benefits, possibilities, and pitfalls were clearly explained to ensure that all participants were fully aware of what they were agreeing to before choosing to participate. It was also highlighted that this study specifically wanted to understand their perspective and highlight their stories.

Power Analysis

To assess if I had enough data, I looked at the depth and the width of the collected information. It may also be interesting to note that finding comparable data to look for standards in other studies was challenging, as almost all studies on these topics do not directly interview the individual with an IDD. Most studies pull data from national health databases or speak to the parent or caregiver. However, in those studies that did directly speak to individuals with IDD, most reported interviewing 6-8 participants (see e.g. Dinora et al., 2020; Ellem et al., 2022). Information power was assessed by how narrow responses are, the density of experiences, variation in experience, and strength of responses (see Malterud et al., 2021). Looking at these areas helped ensure sufficiently rich information was produced. As the researcher, I was mindful that if other ways of speaking about experiences were utilized, this did not distort their responses (Mertens, 2019). I aimed for a range of experiences with their mental health journey to have a broader depth and density of information. With that, I looked for three elements to conclude the data collection portion. (a) recognizable patterns have emerged through interviews, such as standard referral practices and services being offered that are recognized by professionals and self-advocates. (b) that several new or other variations of experiences have emerged. (c), in consultation with key informants, discuss the extent to which the data set gathered is sufficient. After nine thorough interviews, it was determined that the data collection was sufficient.

Data Collection Procedures

The Team

The research team on this project includes me, Melissa Kramer. I have extensive experience working with adults with IDD, working at Inclusion Langley Society, Richmond Society for Community Living and independent respite services for 15 years. I saw firsthand the barriers many individuals face when accessing mental health services. Additionally, throughout my undergraduate degree, my studies focused on the experiences of individuals with IDD. I also presented at several conferences on the experiences of IDD in the workforce. I have dedicated my life to this important area of research.

The thesis supervisor, Dr. Marvin McDonald, has extensive expertise working with marginalized groups and trauma. Dr. McDonald has also supervised numerous thesis projects with a transformative focus. The thesis's second reader, Dr. Estera Boldut, has extensive experience working with individuals with IDD and mental health disorders. Dr. Boldut has extensive supervision expertise. Outside of research, Dr. Boldut works directly with families with children with IDD and mental health diagnoses, ensuring adequate support and services are available.

In addition, several expert key informants are available to support this project. A local self-advocacy group was contacted and they invited me to a meeting to hear about the project. With them, I reviewed all research questions on the intake questionnaire and the full interview to ensure that all materials and questions were in plain language. Input was also taken for the project from this self-advocacy committee to ensure that its direction applies to their experiences. Also, the input from this group influenced the materials and information being presented about the project, with every aim to walk side by side with the research project participants, as Mertens argues (Mertens, 2019).

Data Collection

To begin, a thorough informed consent process was reviewed, and a form was signed before starting the interview (See Appendix D). At times, this was done verbally and consent was verbally given and recorded. Because of the nature of the topic, I went over the details around mental health and trauma openly, ensuring that participants knew they were only being asked to share what they were comfortable with. I was also clear that I was not their counsellor but a researcher. Before beginning the interviews, I put together a list of local counsellors who work with those with IDD to have resources ready in case anything challenging arose during the interview and they felt they needed to discuss it in a therapeutic capacity. Finally, before beginning the interviews, in plain language, I reviewed the basic description of the subjective ideals of behaviour in society (Phelps, 2021). This is because many individuals with IDD have been trained to act in specific ways, specifically when speaking with those without disabilities in a formal setting. The urge to hide behaviours or feelings that may arise naturally has been a common practice for many. The hope was to create a level of comfort and understanding that their experiences, feelings, or thoughts about their situation are welcome in this study, even when they are not socially acceptable.

Interviews occurred in person and over Zoom, depending on the participant's preferences. All measures were taken to have the interview in a setting where the participant felt most comfortable. All interviews were recorded by video on a laptop via Zoom. These recordings, as well as any transcripts, are saved on an encrypted USB to ensure safety.

As I began the interviews, the focus was on giving a voice back to the participants who are at the forefront of the project. This happens naturally with a narrative inquiry. One expert, Munro, looks at the narrative analysis of participants' personal stories as a powerful tool to highlight marginalized experiences (Munro Heady, 2007; Kim, 2016). Heady was also cautions to be aware of the power structure of the interviewer and interviewee (Kim, 2016). Therefore, I highlighted the reality that they are the experts of their own stories, there is no right or wrong answer, and that at the core of it all, the goal is to understand their experiences. Additionally, it was important to make it explicit that power structures are often at play when one person is interviewing another and that every effort was made to create partnership and collaboration.

I conducted semi-structured interviews with the same content for every participant (See Appendix G). Questions were open-ended and worded in a way that allowed the participants to share as openly as they felt comfortable. The narrative approach requires a conversational interview that allows participants to express their experiences, thoughts, feelings, and perceptions. Therefore, it was essential to set the climate of the relationship that allows for storytelling in all its forms (Riessman, 2008). The questions also outlined the importance of understanding their direct experience of what it was like to be them, at that moment, over a span of time, and in their life (Kim, 2016). Questions utilized a two-sentence technique, where the first sentence gives context to the following open-ended question (Kim, 2016). As we have highlighted, many individuals with IDD have yet to have the opportunity to speak directly about their own experiences; adding a small qualifier to support participants in knowing what context the question is being asked was helpful. This approach also supports the integration of the participants having a piece in the creation of the narratives being developed; it reaffirms statements already said before asking the next question and may also support the natural flow of the interview while also being flexible with the direction the participants story is going (Kim, 2016).

Data Analysis

All interviews were transcribed by Zoom in a preliminary fashion. Next, I reviewed each interview recording and corrected and completed the transcripts. I completed all transcriptions while keeping the fundamentals of narrative inquiry and thematic analysis at the forefront of my mind. It was crucial to hear the participants' words and the cadence, tone, rhythm, inflections, or para verbal gestures to get a complete picture of what they were saying. Riessman notes that narratives come in many forms and sizes, ranging from short quick responses to long narratives that develop over several interviews if needed (2008). With that, understanding the nuance of how a participant spoke and explained their stories is just as important as the words they are saying directly. These qualities were also noted throughout the transcription to help pull out the rich stories that are being told.

Thematic Analysis

I utilized a thematic data analysis, which views each transcript and pulls out themes to give a concise view of participants' experiences. In addition to highlighting themes within the data, stories and quotes were also utilized to clarify and emphasize those themes. Whenever possible, participants' original thoughts and words are incorporated into the description of themes.

Thematic analysis was completed in five stages: (a) Organization and preparation of the data, which is done by completing the transcription and ensuring that pseudonyms are used and any other identifiers that the participant has requested be changed, like the program or organization they are associated with would also be changed (Butina, 2015). (b) Understanding a general sense of the data, with the first review of the data, I noted any general themes that have naturally arisen (Butina, 2015). (c) The coding process looked like re-reading the transcripts and noting any reoccurring words, ideas, or patterns that come from the data (Butina, 2015). (d) Categorizing themes, after the coding process is complete, I focused on organizing those codes into categories that represent major findings in the data (Butina, 2015) (e) Interpretation of the data, the final step looked at making meaning of the data, from here, I was able to see any overarching themes or narratives and what those may mean (Butina, 2015). Within those steps, tone, inflections, and cadences were all considered when reviewing transcripts to ensure that words spoken were considered and how a person speaks. To ensure that emphasis is continually focused on the participant's stories, quotes and pieces of stories were utilized in the discussion to highlight participants' abilities to advocate for themselves.

In alignment with Butina’s recommendations, this study also focused on the exploration of implicit meanings within a participant’s experience. Specifically, as Riessman (2007) articulates, the integration of narrative and thematic analysis enables me to uncover deeper meanings and insights within the data. Through thematic analysis, I was able to identify themes and common threads in each participant's story, which helps the reader to understand the narratives that are being expressed (Riessman, 2007). Through narrative analysis, by examining both the thematic content and the narrative storytelling process, researchers can gain a more comprehensive and nuanced perspective on the data, leading to a richer interpretation of the lived experiences being studied (Riessman, 2007). Further, as this project looks specifically at individuals with IDD, this combination is distinctly important. As many individuals with IDD have unique ways of expressing their experiences, needs, and desires, being aware of implicit meanings, non-verbal cues, and diverse ways of being is essential to capture the full meaning of people's experiences. At times, what is not explicitly stated is just as important as the things participants directly said.

Rigour and Validation

Ethical considerations were engaged throughout the project with specific principles that hold to a transformative paradigm and the narrative inquiry and to the well-being of all participants. Additionally, thoughtful consideration was taken for specifically what questions would be asked and if they served the purpose of collecting only the needed data while minimizing any potential harm. Furthermore, an overview of the topics, questions, and any other important information was provided to ensure that each participant was fully aware of what they were agreeing to. Additionally, dynamic consent was ongoing throughout the project. Consent was not asked once, but it is an ongoing process throughout the project. Participants were also only asked to share what they felt comfortable with; participants could withdraw their data up until analysis and were welcome to ask any questions throughout the process. Participants were also welcome to include a support person within the consent process if they desired.

A primary emphasis of the project is the emphasis on first-hand experiences. For this to be successful, all materials and questions were written in plain language, meaning the simplest form of language possible for a given situation. To ensure that all materials were sufficiently in plain language, I had all materials reviewed by key informants on the project. As I have a long-standing relationship with several self-advocate teams in the lower mainland, I attended a self-advocacy meeting in Langley, and the self-advocates on the team reviewed both the intake and full interview questions to ensure the readability and comprehensibility were adequate. This was an incredibly informative experience, and I was able to make several adjustments to questions before starting formal interviews based on their input.

As I have significant experience in the field working with individuals with IDD, it was essential that I assess my bias, bracket my awareness, hear the participant as an individual and deflect assumptions. The interviews were semi-structured so that when a probing question came up reflecting my knowledge and experience in the field and if a probe might generate more richness in the data, then the probes could guide the interview.

Generally, I wanted to ensure that the individual story was what was being told in the interviews, not a version of the story that filtered through my bias. So, when reading transcripts, I acknowledged my preconceived thoughts and perceptions and asked if they were mine or the participants. I endeavoured to put aside my perceptions and immerse myself in the participant’s story and transcript fully. This process was maintained for each transcript and portion of the thematic analysis. With that, holding a transformative paradigm, I aimed to constantly question my assumptions and ideas about the participants, field, or experiences (Phelps, 2021). The goal was always to be open to learning new things and to hold any preconceived ideas lightly in honouring the participants as the experts in the project.

As the study's primary purpose is to highlight the voices of those with IDD, I aimed to ensure that the themes that have arisen from the data were accurate to what the participants wanted to communicate. This was facilitated by reviewing the discussion and results with participants before completing the project. I ensured I am continually highlighting their experiences first and foremost throughout. This added to the rigour because there was actual follow-through with responses to their experiences.

CHAPTER 4: RESULTS

Through nine interviews, several rich themes emerged that highlight the complex experiences and need for better mental health support for individuals with IDD. The first theme demonstrates that mental health support for individuals with IDD has focused on quick fixes to minimize symptoms rather than strengthening the overall well-being of the client being seen. The second theme touches on how an individual's support network has often been a substantial factor in shaping whether the person with an IDD understands their mental health. In this study, a participant's support network was also found to anchor the support they have received for their mental health and their quality of life. The third theme highlighted how participants showed a significant lack of understanding of their mental health. This was highlighted through missing knowledge on what their diagnosis was, their symptoms, how symptoms impacted their lives, what medications they were taking, what the medications were for, and how medications impacted their interactions with others. Finally, the fourth theme encapsulates how many participants previously experienced adverse life or traumatic events, with almost all of them not receiving any counselling or mental health support to help heal from the impact of the event. Figure 1 highlights the order in which I discuss these themes.

Figure 1

Major Themes From the Experiences of Study Participants

Further, this chapter highlights how each theme has directly or indirectly impacted each participant. I also make it clear how the themes impact and build on each other while noting that participants’ experiences were not a linear sequence of events. Instead, I have witnessed the ways in which each participant had their own dynamic and challenging experiences, which they all handled in distinct ways. Lastly, the integrative summary at the end of this chapter highlights how active systemic oppression creates unnecessary barriers for many participants to receive mental health support. In this summary, I discuss how diagnostic overshadowing impacts the client in the room, as well as the future trajectory of mental health services for those with an IDD.

Participant Background

Each participant offered a unique understanding of their experiences. All spoke to the significance of their challenging mental health experiences while also noting their strength and vitality. As previously stated, each participant is more than a simple diagnosis, yet some contextual information can be helpful to accurately understand a person’s experience. For further information about each participant, Table 1 highlights their pseudonyms, ages, IDD diagnoses, mental health markers, living arrangements and typical schedules. The mental health marker is noted as a description rather than as an official diagnosis, as receiving a concrete mental health diagnosis is extremely challenging due to funding, diagnostic overshadowing, and access to resources (Holub et al., 2018). Therefore, the mental health marker includes both diagnosed disorders as well as symptomology that the individual and their support networks have noticed. Both the living arrangements and schedule speak to the level of independence and support each person may be receiving. Living arrangements speak to independence in that those who are more independent may live on their own, and those who need more daily support often live with family or caregivers. The number of days and type of support a person may receive is noted in the weekly schedule. For funded services, the number of days of support and the type of support depends on a multitude of factors such as level of cognitive functioning, funding available when the person applied for services, level of advocacy for support, mental health factors that may impact their ability to attend funded services, and many other complex factors.

Table 1

Self-Advocates Participating in the Study

Pseudonym	Age	IDD Diagnosis	Mental Health Marker	Living Arrangements	Weekly Schedule
Brian	28	ASD	Anxiety	Lives with family	Attends a day program two days a week and receives one-to-one support one day a week
James	45	ASD	Bipolar	Lives with a caregiver	Attends a day program 5 days a week and works providing two mornings a week
Kathy	28	ASD	Anxiety and Depression	Lives independently	Receives one-to-one support four hours a week and works at a coffee shop
Megan	39	Down Syndrome	Depression	Lives independently	Attends a day program one day a week and works at a food court
Randall	52	FASD	Depression	Lives with a caregiver	Attends a day program three days a week
Sophie	49	ASD	Anxiety and Depression	Lives with a caregiver	Attends a day program two days a week
Suzie	46	ASD	Depression	Lives with a caregiver	Attends a day program three days a week
Tyler	38	FASD	Depression	Lives with a caregiver	Attends a day program two days a week and works at a car dealership
Victoria	41	ASD	Depression	Lives with a caregiver	Attends a day program five days a week

Note: This table indicates the background information for the participants in the study. Autism spectrum disorder (ASD), fetal alcohol syndrome (FASD). Mental health marker is symptomology or diagnoses a participant may exhibit. Living arrangements and weekly schedules indicate the level of independence a person may have.

Individualism vs. Strong Relationality

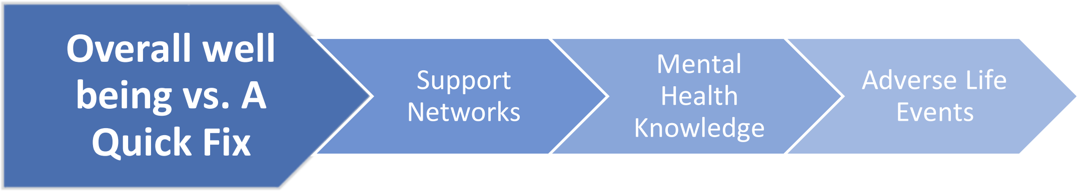
Culturally, there is a strong emphasis on individualism in mainstream Canadian society. The goal is often for individuals not to need to rely on anyone but themselves. Even within services funded by CLBC, there is a strong emphasis on independence, which often involves living independently, working in the community, and needing as little support as possible. However, what is often missed is the importance of strong relationality, where each person brings something important to the relationship that is mutually beneficial (Flowers et al., 2016). This relational focus moves away from a narrow version of individualistic happiness and towards connection as a central feature of health and well-being. Many people with IDD are more reliant on their families or other members of their support networks longer than people who do not have a disability. At times, this is viewed as a familial or cultural burden. However, through a strong relationality lens, these relationships can be viewed as focusing on the meaningful connections that they bring. Mutual relationships can bring purpose, reward, joy, connection, and peace to those in the relationship.

All nine of the participants spoke about various important people in their lives. Through life circumstances, they were often more reliant on their families and caregivers than most adults. However, as I spoke to each participant, their gratefulness for the support they received exuded from them. Additionally, as I had the chance to speak to some of the people in their support networks, similar expressions of appreciation and adoration were common occurrences. Individuals with IDD, and specifically the nine participants, were not simply a burden on their families who needed to strive for more independence; they were valued members of their families and community and were in mutually beneficial relationships where sharing the burdens of life was welcomed. What this begins to highlight is that the option of independence can be important, but it is not always the primary life goal. In contrast to common stereotypes, those who are not working towards greater independence are not considered an inherent burden to those around them. In other words, strong relationality was evident in the lives of the study participants (Flowers et al., 2016). Strong relationality was also a benefit to not only the participants but also to the people in their support networks.

Overall Well-Being Versus a Quick Fix

Figure 2

Major Themes – Overall Well-Being Versus a Quick Fix



Everyone who participated in the study had a unique experience accessing and receiving mental health services. They all also varied in how they came to realize that they were experiencing mental health symptoms and how they distinguished their need for help from just going through the ups and downs of life. Overall, eight out of the nine participants reported experiencing significant mental health symptoms that led them to receive services through Developmental Disability Mental Health Services (DDMH). The one who did not receive DDMH services also reported significant mental health symptoms; however, he lived in an area where it was challenging to access their direct services, so he relied on his family doctor for support. Through DDMH, the majority of participants reported seeing a psychiatrist only once or twice, being prescribed medication, having one follow-up to ensure they were stabilized, and then having their files closed. Several participants said they were seen five to ten years ago and have not been seen again for an official medical evaluation.

However, all those participants reported their mental health symptomology still impacts their daily lives. Specifically, what was clearly lacking was any education on their diagnosis or symptoms. There was also very little understanding of their prescribed medications, side effects, and if the side effects were something to cause concern. There was no medical support that promoted health education. Two participants, James and Victoria specifically noted adverse physical side effects of their medication. They stated that when they mentioned the side effects to their doctor or psychiatrist, they were just told it was something they would have to deal with. However, for these specific participants, the side effects of their medication were impacting their daily lives and causing emotional disturbance because of their frustration with their new physical ailments.

The missed opportunity to provide health education at the time of diagnosis or prescription of medication has led to a fundamental lack of understanding about mental health among participants. Diagnostic overshadowing is drastically impacting the health care that individuals with IDD are receiving. Doctors are bypassing the patients due to their disability and making assumptions without fully investigating the full range of causes of their mental health symptoms. They are also creating unnecessary barriers to health education due to their beliefs about this group of people. It appears that the psychiatrist or doctor assumes the individual receiving the support does not have the cognitive ability to understand the information they are providing. Instead, the professionals often rely on the caregivers, family, or support staff to receive and translate that information for the individual with an IDD. However, if a person with an IDD is diagnosed with depression or bipolar disorder, the psychiatrist is also not providing sufficient education to the support networks on symptomology, mental health resources such as counselling or group counselling, or how best to support the individual in a mental health crisis.

These gaps have led to maladaptive coping strategies by these individuals that are often ineffective and, at times, harmful to the individual's overall well-being. These neglected features of health care also drastically increase the likelihood of another mental health breakdown in the future as the individuals are not being supported effectively.

Primary, Secondary, and Tertiary Prevention

Diagnostic overshadowing, systemic pressures, and barriers to health care have created a system where patients are not receiving support through primary prevention but rather only through secondary or tertiary prevention. The primary prevention approach is when a client is known to struggle with early coping efforts, but support comes in to strengthen coping before symptoms arise. A doctor or support network may know about an individual's circumstances or vulnerability in coping resources and provide scaffolding support ahead of time in order to ensure that the person has what they need in order to prevent symptomology from arising. Likewise, if symptoms do arise, the person can mobilize the skills and resources to be able to support the person effectively. The secondary prevention approach focuses on help and support once the patient or their support network notices symptomology, and support comes in to ensure that symptomology does not get any worse. Tertiary prevention focuses on support after things have fallen apart. At this point, recovery is often significantly longer, and more damage is done because the person has suffered to the point of increasing dysfunction. In the current mental health system for those with IDD, patients are often only receiving support when symptomology is drastically impacting their daily lives or when they are in a full-blown crisis. Therefore, individuals with IDD typically receive no primary prevention but only secondary or tertiary prevention.

As noted in the literature review, one of the best ways to reduce mental health symptomology and strengthen coping is through medication with therapeutic support (Guideline Development Panel, 2022). Additionally, DDMH highlights that they offer group and individual counselling services (Fraser Health, n.d.). However, through the nine interviews, all of which reported significant mental health symptomology, none were offered counselling. Additionally, many also reported a traumatic event at some point in their life, which research highlights can be a risk factor for a mental health diagnosis (Kildahl et al., 2020; Wigham et al., 2011). However, no participants reported receiving services specifically for their mental health or to process the adverse life events that they have experienced. For example, Randall noted that he requested counselling through DDMH; however, he was told that he was “too high functioning” to receive their counselling services. He eventually received support through an agency separate from DDMH. Even when Randall, who receives CLBC funding, has a diagnosed mental health disorder through DDMH and specifically requests counselling, it was denied. A failure to act on secondary prevention led to Randall turning to alcohol and other substances to cope with the painful memories he often experienced. Randall was able to receive counselling through Addictions Services through Fraser Health. Through that counselling experience, he reported feeling seen and understood for one of the first times in his life. Randall also noted that he learned new coping strategies to handle the memories that arose at times. Randall also stated that he began to build confidence in himself and was learning how to see value in his life. If a primary prevention approach had been utilized, Randall may have had better tools to cope with his painful memories.

Aspects of Diagnostic Overshadowing

Medical Professionals' Underestimation of Abilities. Several participants noted that their doctors or psychiatrists did not always take their concerns about their mental health seriously. For many individuals with IDDs, there appears to be a breakdown of communication due to the professional's opinion of the perceived and actual cognitive abilities of their patient. This family of processes can be described as diagnostic overshadowing. While traditionally, this looks at symptoms being assumed to be part of one's disability, diagnostic overshadowing can also go further into the treatment and long-term care after a diagnosis. With standardized care, those who function outside of “normal” ranges of functioning are often missed. As a result, the missing education, resources, and therapeutic support has led to some individuals with IDD suffering greater and more prolonged distress than if they had been supported with a more equitable distribution of resources. Diagnostic overshadowing also includes the professional's view of the individual and their perception of the patient's capacity to learn and understand information. Many individuals with IDD can understand their own mental health, but due to the assumptions a professional may have about them, time and resources are not taken to support individuals with IDD in that learning. Some professionals hold to a clear underestimation of the individuals with IDD cognitive abilities to understand their mental health.

Incorrect Assumptions About Life-Skill Abilities of an Individual. Diagnostic overshadowing impacts how many professionals view an individual with an IDD's ability to function in daily life. Among all participants in this study, many could not clearly state the symptoms and ways in which they coped with their mental health symptomology. The lack of expectation that many medical professionals hold highlights the presumption that participants lack the life skills and abilities to handle their mental health and follow through with tools that may improve their lives. These assumptions then continue to perpetuate a cycle of low expectations for individuals with IDD. Individuals with IDD are not being offered a chance to grow, heal, and learn, and no one ever stops to assess if the patient has the skills to improve their knowledge about mental health and increase their awareness of ways to cope.

Ability to Process Traumatic Events. Finally, diagnostic overshadowing also seeps into the assumptions about an individual with an IDDs ability or need to process the traumatic events in their lives. Most participants in this study have experienced significant traumatic events. Following those events, many participants reported experiencing noticeable mental health symptoms. These were often communicated by a noticeable difference in a participant's mood, vocalizing constant worry, and, at times, suicidal ideation. However, no one who mentioned these experiences was offered any therapeutic support after the event or when the noticeable symptomology began. There is a clear lack of understanding that those with IDD can and should have the opportunity to process their traumatic experiences.

Diagnostic Overshadowing Experiences. Victoria noted that she was on medication for her low moods and sporadic ups and downs. Her experience with medication is that it has caused significant gastrointestinal distress, which has caused her to, at times, isolate herself due to physical discomfort and emotional vulnerability. When asked if she had spoken to her doctor about it, she said he did not listen. Further, this participant reported having minimal friendships due to other people irritating her. In speaking to her support network, they reported that while her mental health was relatively stable, her irritability has consistently increased, which has caused difficulty in almost every relationship in her life. While we presume Victoria is on the medication that best supports her mental stability, there has been no information given to her about how to handle the physical side effects or, more importantly, how to cope with the psychological and emotional realities of having depression or a mood disorder. When Victoria was asked what tools or life skills she knows about, she indicated that she only tells people to leave her alone and goes outside to spend time by herself, which her support network confirmed. When asked about symptomology, she reported that she always feels down. Victoria also disclosed that she experienced significant trauma in her childhood. However, she has never been offered therapeutic support to understand her mental health or process her adverse life events.

Megan also noted that she experienced multiple traumatic events in her 20s. Specifically, she was sexually assaulted by a stranger, had an abusive boyfriend, and had instability in many relationships in her life. While she presents as very independent, she knows very little about her own mental health. This was noticed by her lack of awareness of her own mental health symptoms. Further, she could not identify what the medications she was taking were for. When asked about how Megan takes care of her mental health, she noted that she tries not to think about the hard times in her life. While Megan is objectively doing well, living independently, and working a part-time job, she also struggles to discuss anything about her past, Megan changing the subject or speaking to off-topic memories. When speaking to her mental health, she noted that at times she feels down but utilizes distraction so that she does not think about it anymore. Megan has the cognitive ability to process her life experiences; however, she has not received any opportunities or access to services to be able to do that.

As noted, the majority of participants were referred to and briefly seen by DDMH. Participants were primarily seen because their mental health symptoms were at a secondary or tertiary prevention level and actively interrupting their daily lives or in active crisis. Most were seen only for a brief assessment and prescription of medication before having their files closed. While DDMH advertises that it offers counselling services, they are very rarely accessible. Table

2 below summarizes a breakdown of participants' understanding of their DDMH mental health support, medications, and symptoms.

Table 2

Mental Health Understandings

Question	Participant Results
Participants who were seen by DDMH	8 out of 9
Participants who were on medication for mental health symptoms	8 out of 9
Participants who could name what their medication was for	5 out of 9
Participants whose results indicated that their mental health impacted their daily life	9 out of 9
Participants who could clearly state their mental health symptoms	3 out of 9

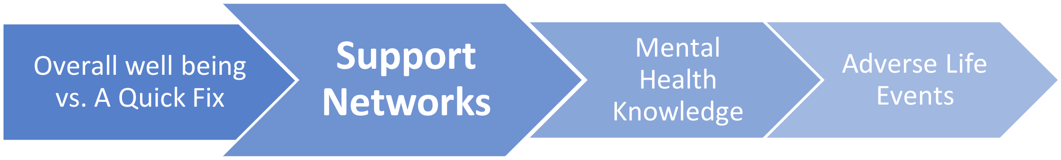
Note: This table summarizes a breakdown of participants' understanding of their DDMH mental health support, medications, and symptoms.

As highlighted in Table 2, there is a distinct gap in the understanding of participants' mental symptoms and how these symptoms actively impact their daily lives. There is a massive missed opportunity to educate participants about themselves, their mental health symptomology, and ways to improve their quality of life. However, this type of intervention would need to take place in the primary prevention stage, where practitioners empower and enable individuals with IDD to learn about themselves and their mental health.

Support Networks

Figure 3

Major Themes – Support Networks



A person's support network can consist of family, friends, caregivers, program staff, community members, and many others who may know and care about a supported person. Sometimes, a person's support network may be small. Others may have big teams surrounding them, ensuring they are well cared for. Either way, throughout the data, it was consistent that those who had even one person in their life supporting them well through their mental health journey were far more aware of their mental health symptomology and able to advocate for their needs. If at least one support person is educated in mental health and provides an adequate understanding of symptomology, those participants were able to name their mental health diagnosis or symptomology much more easily than those who did not report having someone supporting them.

Kathy noted coming from a challenging home environment where she reported that she was over-medicated. As she aged into adulthood, she found a member of support staff who supported her in finding her independence from these family members, moving into independent living, finding a psychologist separate from her family, and eventually was able to titrate off all mental health medication and is now taking a holistic approach to her mental health. Kathy noted feeling better than she ever had in her life. She also stated that her support network also supported her with a better understanding of ways to regulate her anxiety, how to know what she is experiencing increased anxiety, and worked with her to understand herself rather than medicate problem behaviour.

Brian spoke about the fact that due to the location where he lived, he did not have access to DDMH services or psychological care. However, he noted that he had incredible caregivers and family close by who were there for him when he was feeling down. His support staff also noted that due to living in the interior of B.C., services were very limited, but that the benefits of a small community were that everyone watched out for Brian. So even on his challenging days when he struggled with his anxiety he never had to face it alone.

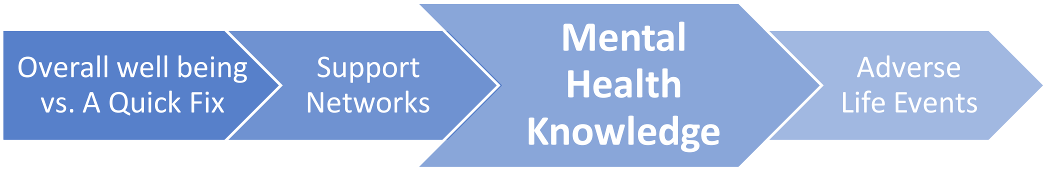
Randall highlighted how, due to being well-spoken, he has often been denied traditional CLBC or DDMH support. However, as he is aging, he has noted a decline in his mental health and does not know where to turn. This participant noted having an incredibly supportive caregiver who helped him find other avenues for counselling support when he was turned away.

As these examples show, an effective support network is critical to a more robust understanding of mental health. However, the reality is that it is up to the support network to become independently educated on mental health and various accessible supports. Unless the support networks have existing knowledge on the topic, most would have to seek out the resources that could be available for the individual they are supporting. The search for mental health services is often reported as a frustrating and slow process. One critical need is a robust understanding of trauma-informed training for all caregivers and staff. For example, first responders receive basic levels of trauma-informed training to be able to approach challenging situations with a level of understanding that can meet the needs of those they are serving. Similarly, if people in support networks had a base of understanding trauma-informed practices, they too, could approach those they are supporting with greater and likely more effective support.

Mental Health Knowledge

Figure 4

Major Themes – Mental Health Knowledge



The absence of mental health knowledge has been a theme throughout the results. In this section, I specifically look at how this lack of knowledge hinders a person's ability to advocate for themselves, to improve their well-being, or to maintain relationships, and also increases the possibility of triggering further mental health challenges.

Self-Advocacy

Self-advocacy is a prominent topic within the disability community for good reason. This emphasis promotes knowledge and continuing education, speaking directly to the individual about their needs and desires, and increases self-awareness for the individual supported. In many ways, the self-advocacy movement has done phenomenal work in ensuring that individuals with IDD know about their rights to advocate for their needs. When speaking specifically about mental health in participant interviews, a gap in knowledge and self-awareness was highlighted. All participants understood on some level that they were self-advocates and had the right to choose in their lives. However, with the lack of understanding of mental health symptomology and growth opportunities, many participants noted making choices that could directly impact their mental health in negative ways. Victoria said that she does not participate in anything at the day program when she feels down. She sits by herself “because it’s my right,” she noted. James mentioned how people do not always want to spend time with him, without realizing that at times his manic symptoms can be jarring to others. James stated that “the rules are we all have to be nice,” without him realizing that at times, he can come across as unkind. Self-advocacy is being discussed as an empowering aspiration without providing scaffolding support for life skills or knowledge of how to interact with others in the mental health space.

This kind of discussion and observation during interviews led to the line of questioning around the participant’s understanding of their mental health diagnosis, their knowledge of their symptoms, and how to know their own experience well enough to put words to it. Through these conversations, the results were distinctive in that participants either knew about their mental health or they did not. As mentioned above, explicit support from a caregiver was evident for those that did. Kathy noted her desire to titrate off medication. Through support staff going above and beyond their typical requirements, the participant was able to find a new psychologist and was supported through this process. Several years later, she noted that she could tell when she was feeling anxious or nervous because she began talking too fast or people indicated that they could not understand her.

Tyler noted that although he does not fully understand his mental health, he knows he is feeling down when he begins to feel sad all the time. Through that sadness, he reported that he can sometimes be mean to the people he cares about. He reported that recently, he ended up isolating and refusing to leave the house. Again, due to excellent caregivers and support staff, he discussed a situation where a support staff came by his home at his sister’s request to check in and see if she could support him at all. Having that external person come in and provide that support helped Tyler to know that he had been struggling with his mental health and was able to resolve some tension at home and get the mental health support he needed to come back to baseline.

These examples highlight the importance of having some vocabulary about feelings, knowing yourself well enough to know if you are fluctuating in mood, and knowing who to reach out to if you need support. However, not everyone can articulate their emotional needs and sensations. Through trauma-informed training, counselling, and group counselling, individuals with IDD could become more fluent in these conversations and hopefully work toward better communication and self-advocacy about their needs.

No Descriptions of Diagnoses or Symptomology

Though some participants knew about their mental health, many others were unaware of their mental health experiences and symptomology. This lack of awareness was often due to no one explaining their mental health diagnosis and the common experiences or symptomologies to them. Likewise, a common gap was having no one pointing out that, at times, their behaviour may be due to mental health symptoms and addressing them holistically. Instead, often, a behavioural modification approach was noted. A holistic approach to mental health views the person as a whole complex being that may need layered support to help with their mental health. Often, holistic mental health support focuses on current factors in a person’s life that may be impacting their mental health, past life events that may have caused trauma that need to be processed, and any environmental factors that may be causing distress. At times, holistic support is utilized in conjunction with medication, which can be beneficial. What is typically utilized in the current system of support is behavioural modification which focuses on the changing of behaviour through reinforcement or punishment. Behavioural modification, as it is commonly practiced, is primarily focused on forcing a behaviour change regardless of what is happening internally and externally to the person exhibiting the behaviour.

Suzie mentioned that she often feels down, noting “silly ideas” popping into her head. When asked who she talks to about those ideas, she said she has been encouraged not to discuss them. This same client has a long history of depressive episodes and multiple reported traumatic experiences and has never received mental health or therapeutic support. The approach she has received is a behavioural modification program guiding her to simply stop thinking about her suicidal ideation. Rather, if a holistic approach were utilized, the focus would be on understanding why she was saying those things and providing support to help her process why she is experiencing suicidal ideation and what support Suzie needs to minimize suicidal thoughts.

Sophie, who also has depressive moods and longer episodes, noted that she often feels like nobody likes her. Support staff noted that she was often tearful for days and then bounced back and seemed to feel better. She reported feeling down and just wanting to stay home. The support staff noted that she gets along well with everyone but that during her downtimes, engaging with what was happening in the program was a challenge. For program staff, their focus is active participation. So, on Sophie’s challenging days, she was encouraged to put aside the sad feelings and to actively engage as though she was not in a depressive state.

Unintentionally, due to the lack of knowledge about mental health symptoms for individuals with IDD and their support networks, there is a strong focus on behaviour rather than mental well-being. Due to that, rather than a person’s mental health symptomology being acknowledged or handled in a way that is clinically proven effective, there is a focus on individuals staying to their scheduled activity and following the rules of day programs. While I respect that programs and agencies are not entirely at fault for this model, when speaking to mental health, this is often not conducive to individuals' long-term mental stability. It is okay for people to be encouraged on a tough day to carry on and join in with the group; however, when this goes on for long periods, individuals with IDD may inadvertently learn not to acknowledge their mental health cues but to follow the status quo situation of the day. However, when that happens, often their mental health symptoms can increase without any resolution and become more challenging than if the participant had space to process their symptoms in a timely fashion. As mentioned in Susie's experience, her depressive moods were constant. Susie is an agreeable person who, even on her most challenging days, would often carry on with the activities at her day program. However, due to that, she has never received the medical intervention that she likely needs.

Further, those who do not follow the status quo may be then labelled as causing challenging behaviours. This would then create a dynamic within the program where staff or specialists are asked to develop a behavioural modification plan for the client to push the client into participation. Again, this approach continues to perpetuate misinformation about mental health, expectations of individuals experiencing mental health symptomology and the best ways to support them. This also does not leave room for evidence and research based interventions for those with mental health symptomology. If Susie's moods interrupted her day program, it would be significantly more likely that she would have received mental health services for her depression by now. However, because she is willing to participate in her day program even when she experiences depressive symptoms, she has never had the opportunity to have appropriate mental health support.

Within this complex situation is also now the reality that many participants noted negative personality traits about themselves which, when looked at objectively, can be recognized as mental health symptomology. For example, James, who lives with bipolar one disorder and often experiences manic symptomology, noted, “I know I shouldn’t get too hyper.” Kathy, who experiences anxiety, noted, “I talk too fast, and no one understands me.” Suzie, who has depression and suicidal ideation, stated, “I have silly ideas, I know I should stop.” And, Tyler noted, “I just get angry and yell.” In each of these conversations, they discussed their symptomology as character or personality flaws that they just needed to change. These are resounding examples of consequences when a person has been given misdirection about their mental health and common symptomology. In these circumstances, a person begins to view themselves as flawed rather than noting a symptom of a mental health diagnosis that can be alleviated when receiving skilled support. When proper care and support are not provided, individuals may develop a view of self as flawed due to a lack of control of acceptable behaviour rather than focusing on the realities of mental health symptomology. However, when the patient’s symptoms are taken seriously and mental health support is provided, then often that person can find better ways to cope with the symptoms they experience. For example, Brian noted significant levels of anxiety. However, Brian immediately also noted the tools he utilizes to support his mental health, such as deep breathing, talking to his support staff, getting some fresh air, and, if he needs a break, taking it. Due to Brian’s location, he has not been officially assessed by a psychiatrist and his support worker noted that they primarily utilize holistic approaches in conjunction with medication to support his overall well-being.

Adverse Life Events

Figure 5

Major Themes – Adverse Life Events

The results of the nine participants were also consistent with the literature in that many experienced adverse life events or specific traumatic events in their lives. With those experiences, none reported receiving therapeutic support to process these experiences. Throughout the interviews, the participants casually mentioned these events as if being treated that way was typical behaviour. Highlighted in Table Three are the results of reported adverse or traumatic life events of the participants.

Table 3

Adverse Life Events

Question	Participant Results
Experienced an adverse or traumatic life event	6 out of 9
Offered counselling after the event was reported	0 out of 6
The event(s) come up for the participants regularly	6 out of 6

Note: Reported traumatic life events, if they think about the events very often, and if counselling services were ever offered to the participants.

Suzie noted that her previous caregiver had physically assaulted her. Recently, she saw this caregiver in public and immediately began to feel panicked and uneasy, so she hid in the handy dart. The police are involved in this abuse case. Yet, she was not offered any support through DDMH, CLBC, or Victim Services to process her experience. James mentioned throughout the interview that he does not like his caregivers; through that conversation, he disclosed that he had “an awful caregiver who was very mean to him” when he was younger. His support staff now noted that he has struggled to stay with a caregiver for more than two years because a situation often triggers him and then he becomes explosive toward the current caregiver. Additionally, support staff noted that if any memories arise for him regarding his childhood caregiver, he begins to ruminate and become angry. The staff often try to distract him and move him away from the topic. He has never been offered counselling to process those childhood experiences. However, he has worked with multiple behavioural interventionists to help with anger management with little success.

Kathy noted extensive parental abuse and medical mistreatment. She explained that her mother struggled with her own mental health, and it was assumed that due to the participant’s autism diagnosis, she likely would too. Due to that, over her childhood, she was prescribed multiple anti-psychotic medications to help her symptomology. When the participant became an adult, she could differentiate from her family and, through her day service, received the support needed to move away from her family. Afterward, she advocated for her medical support, and she then chose to titrate off all medication. Today, she states that she is doing okay but still has a lot of anxiety. When asked if she’d ever consider counselling, she mentioned that she sometimes talks to staff but that she does not know what a counsellor is or what they do. So, even with systemic knowledge of abuse, overreaching power into her life, and overmedication, the participant was not offered any therapeutic support.

Finally, Megan reported a sexual assault that had happened ten years prior. While she received medical support, she was never offered any resources to process what happened to her. Shortly after, she was diagnosed with depression and prescribed an anti-depressant. Today, Megan noted that she does whatever she can to not think about the incident.

While all the participants have learned to cope with the results of their adverse life experiences, the reality is that for many of them, these experiences have had a lasting effect. Whether that be an emotional vulnerability, quick triggers around certain topics, relational dynamics, reports of abuse or neglect, or many other realities. Additionally, for all the participants, therapeutic support was never offered to process these traumatic experiences. This reality again highlights the systemic oppression that many experience where the focus is on the minimization of disruptive symptoms rather than supporting understanding of why a person copes the way they do and tools to support healthier ways to cope.

Integrative Summary

The experiences of the nine participants were equally eye-opening and heartbreaking. As their experiences are distilled, at the core, there is an overarching pattern of systemic oppression, diagnostic overshadowing, lack of privilege, and disempowerment. We also can see how a person’s support network can be the cornerstone of their well-being, and yet, the current system provides almost no resources to support families and caregivers as they walk alongside those with IDDs and a mental health diagnosis. Many participants and their support networks are not handling these challenging situations well because everyone is grasping for any resources they can find rather than being supported and understood in relevant ways. Finally, we also saw that participants experienced traumatic events. Consistent with the literature, many individuals with IDD experienced traumatic events and were provided with no resources or support to therapeutically process these situations. We also saw how these events were still impacting their lives today. Through this, the systemic oppression was highlighted by the systematic neglect of preventive approaches to promote recovery and well-being. A system that focuses on short-term costs without assessing the long-term financial deficits creates a harmful system where individuals with IDD are suffering unnecessarily and excessive system costs are magnified.

The results centred around the first-hand experiences of people with an IDD who have experienced mental health symptomology. What was not stated explicitly by participants was, at times, equally as important as what was said directly. A strong pattern was the incomplete understanding of their mental well-being. An easy misconstrual would be that these participants, or, generally, those with IDD, do not have the cognitive ability to understand complex mental health issues. However, in line with the voices of self-advocates, I would challenge that prejudice with the reality that most do have the ability. However, they experience systemic oppression through a government system that does not allow them equal access to mental health services. Limiting access limits individuals with IDD's ability to learn, heal, grow, and take power back into their own hands. This keeps an entire group bound and reliant on a government-funded system.

We can also acknowledge that the care many people in this community receive focuses more on quick fixes than overall well-being. Through the evidence of the nine participants, their psychiatric support concentrates solely on the minimization of symptoms rather than a holistic approach. That can be concluded by the prevalence of quick prescription of medication targeted at reducing symptomology. The resulting lack of therapeutic or holistic mental health support sabotages which can aid in long-lasting well-being as well as deflecting many improvements in symptom control. We also need to recognize the reality that many individuals only began receiving support through DDMH when their symptomology began interrupting their funded services. Participants' files were also closed when those same systems stated that they reached a level of stability that no longer caused any issues within their funded service. This narrow focus on the quick fix deflects available benefits from primary prevention. Even if unintentional, there is a consistent theme of systemic oppression that prioritizes maintaining current services and neglects the individual mental health support that a person may need.

Another resounding element is that access to appropriate resources should not be considered a privilege and, therefore, optional in mental health support. Many individuals with IDD may need services and written material in plain language, this should not be reserved just for those who are in a privileged position to pay for it privately. While the DDMH website highlights individual, group, play, and art therapy, none of the participants or anyone in the focus group at the beginning of this study were ever offered access to these services. As previously noted, Tyler, who has a diagnosed disability and mental health disorder, specifically asked for counselling through DDMH and was turned away due to being too "high functioning." There is an element of injustice in advertising such services and denying access to those who need them.

What was also incredibly clear was that each person's support network was the cornerstone of their overall well-being. Those who had great support had more access to services than those who had minimal support in their lives. What was consistent was that those without much support seemed to struggle more obviously with their mental health symptoms. These participants also conceptualized these symptoms as personality traits due to not having access to mental health services that could better scaffold their understanding of mental health. It was clear that those who had robust support systems had a smoother time accessing mental health services. However, in both categories, it was the caregiver's initiative that connected the individual to support or not. It was also the individual's caregiver's effort to become more knowledgeable on these topics.

Holding onto the thread of systemic oppression to weave it through, caregivers are hired and paid the same amount whether they choose to take the initiative and learn about mental health or not. They are paid the same amount, whether they support the individual in accessing mental health services or not. Systemically, there is no emphasis on a caregiver or other support network members to support the individual to access mental health services. Additionally, there is no funding put into training support networks about mental health and ways to support those who are struggling. Even though the literature has highlighted a clear connection between the support networks' knowledge of mental health and the individual's overall well-being, this is not something that is funded or considered a priority for the funding system.

Finally, and arguably most importantly, all participants who reported traumatic events casually mentioned horrific events as if they meant nothing. Within the interview questions, there were no questions about trauma or adverse life events, all these reports simply came up when we were talking about their mental health. This may be coincidental, or it may be evidence that when speaking about their mental health, each of the participants automatically thinks about those challenging life events that they experienced. Further, regardless of this evidence, there is extensive research indicating that individuals with IDD experience significantly more traumatic events. Most often, they respond similarly to those without a disability, which means they often receive a mental health diagnosis. Even with that research being clear for many years, access to therapeutic support for those with disabilities has not increased. This observation continues to highlight the systemic oppression and quick-fix approach that does not address the whole person but simply their symptomology.

The results highlighted the participants' complex experiences. Each participant’s experience differed from the other. What was clear was the strength and resiliency of each participant. The ways in which each person coped were often not conducive to long-term well-being. However, for them, these maladaptive coping strategies helped them function in their daily lives. This research highlights that we must approach mental health services in a more flexible and understanding way. Services cannot be one size fits all; we must provide appropriate support for individuals with IDD that go beyond medication prescription and view each individual as a whole and holistic being that needs services.

CHAPTER 5: DISCUSSION

Findings throughout this study highlighted some important factors that impact the mental health of individuals with IDD mental health and their ability to cope. Specifically, there are many ways in which diagnostic overshadowing impacts care provided for individuals with IDD and their ability to access services. Systemic oppression creates unnecessary barriers for many to access mental health resources, which then has prevented participants from gaining access to mental health services that would support them in understanding effective ways to cope. Additionally, for individuals with IDD, the importance of having a support network to access services was evident. Finally, there are common and consistent experiences of traumatic events with no emotional or mental health support after those experiences. In this discussion chapter, I highlight the importance of amplifying participants' voices and viewing individuals with IDD as deserving of access to resources.

Many new and distinct findings were evident. Each interview with participants had a common pattern of embodying systemic oppression. The embodiment of systemic oppression is clear through minimal funding for mental health resources and the barriers a person experiences when attempting to access available services. These barriers compound the systemic oppression a person with an IDD and a mental health disorder experiences when advocating for their rights. There was also a consistent theme that many face language barriers when accessing resources not in plain language.

Systemic Oppression within a Government Funded System

Throughout the literature review, it was highlighted that for many individuals with IDD, structural, economic, and cultural exclusion prominently exists within society, and many of the participants in this study have also experienced this (Arstein-Kerslake & Black, 2020). For many participants, accessing mental health resources has been an incredibly discouraging experience. This was often due to the systemic barriers in place to prevent a person from accessing support. These barriers often looked like excessive wait times, minimal follow-up from professionals, and narrow criteria to access services for which many did not qualify. Additionally, there are very services to access for individuals with IDD to utilize when experiencing mental health symptomology; therefore, many participants and people in their support networks noted feeling stuck with nowhere to turn for help when mental health symptoms arose.

These barriers are concerning because the literature has highlighted the importance of mental health support and the likelihood of a person with a disability experiencing a mental health disorder (Cook & Hole, 2021; Kildahl et al., 2020; Wigham et al., 2011). However, this support is often not provided even with availability of research, with high numbers of people experiencing these symptoms, and with individuals and their support networks asking for more resources. The current funding system has focused on controlling short-term costs, which in turn creates long-term financial deficits. This study's results highlight that most participants only received support when their symptomology could be addressed by secondary or tertiary prevention approaches because, at that point, participants would already be experiencing mental health symptoms and potentially in crisis. When the funding system steps in at this point, likely the medical interventions often will be greater, which leads to unnecessary suffering and financial costs on the way to recovery.

Suzie, for example, spoke of being present when her partner died by suicide six years ago. Since then, she noted that she has asked for counselling, but the request has never been taken seriously. Over the last year, she also experienced caregiver abuse. The caregiver has been charged with abuse legally and is now going through the court system. However, Suzie again has never been offered therapeutic support through CLBC or victim services and has not had private access. Suzie also noted that when things get hard, she often has “silly ideas.” When asked more about those thoughts, she noted that when those challenging memories come up, it feels “really hard” for her. Looking at Suzie’s example, she has experienced significant amounts of trauma in her lifetime. Many of these situations were also known by the authorities and CLBC, however, counselling was never offered to her. So now, Suzie battles her suicidal ideation alone, just trying her best not to think about it. Likely, if Suzie were ever to receive support, it would be because she is in active crisis. Again, this highlights the focus on tertiary prevention rather than offering Suzie counselling now, which could prevent her mental health status from worsening.

This type of discrimination is common among individuals with IDD. Various factors influence why this happens. However, it is important also to state that it is an injustice that it is happening at all. Suzie deserves the opportunity to process these traumatic experiences. If we do not change the institutionalized and systemic discrimination, situations like Suzie’s will continue to happen.

Diagnostic Overshadowing

The evidence of diagnostic overshadowing throughout the results was profound. As the literature review highlighted, diagnostic overshadowing is when blame for symptoms or continued struggle is often put on the person with an IDD rather than acknowledging the problems within the system (Molloy et al., 2020). Diagnostic overshadowing often goes beyond a person seeking mental health support or a diagnosis. Diagnostic overshadowing also impacts how that person learns about their mental health disorder, receives support, and understands themselves as full humans.

There have been minimal resources going into understanding the complexities of a person with a disability. While mental health resources exist for individuals with IDD in BC, what is clear is that they are not sufficient. Simply naming a funded resource for individuals with IDD does not ensure that people are receiving appropriate support. What is clear is that the number of barriers and exclusion criteria for individuals with IDD limits their abilities to access supports created specifically for them. As detailed in the results, this process dehumanizes individuals with IDD. Many of these resources focus solely on the participant's disability rather than seeing participants as complex human beings who may also be experiencing mental health symptoms.

James' support network noted that he experiences significant increases and decreases in his moods. The lack of consistency in his mood was said to impact every area of his life. For instance, James is an incredibly determined person who has the desire to find employment. However, due to his fluctuation in mood, it has been challenging for him to hold down a steady job. After years of medical appointments and several specialists, James was diagnosed with bipolar disorder and prescribed a medication that helped stabilize his moods. Unfortunately, James still experiences fluctuating moods, most significantly when a topic he finds triggering is mentioned. James's experience highlights the question that if he had been seen earlier, and a diagnosis did not take several years, could he have received the support he needed earlier? There is also evidence that if he were to be able to access therapy to process those triggering topics, his mood may stabilize further, and he would be able to access consistent employment.

For James, as he saw medical professionals, the focus was on how his ASD presented. Behavioural interventionist services were utilized to try to change the fluctuation in his mood and behaviour with little success. However, when James finally saw a doctor who did not engage in diagnostic overshadowing, they saw that many of James's symptoms were outside of a typical

ASD diagnosis. When the doctor began spending the time to investigate further, James was able to receive an accurate diagnosis and receive appropriate medical interventions for bipolar disorder that changed his life for the better.

The best way to combat diagnostic overshadowing is through education and advocacy. The dynamic power imbalance in the medical field comes with unique challenges. Often, medical professionals are seen as an authoritative person. In medical circumstances, many individuals with IDD and their support networks may struggle to advocate for their needs because, systemically, it is assumed that the medical professional is the expert. However, diagnostic overshadowing often highlights that medical professionals are not taking the time to learn about each patient they are seeing. For change to happen, there must be a shift in perspective that individuals with IDD are the experts of their own experiences. Medical professionals must be expected to recognize the individual with an IDD as a whole person and support them holistically. This shift also requires medical professionals to be flexible with their approaches and resources, realizing that this cannot be a one-size-fits-all service.

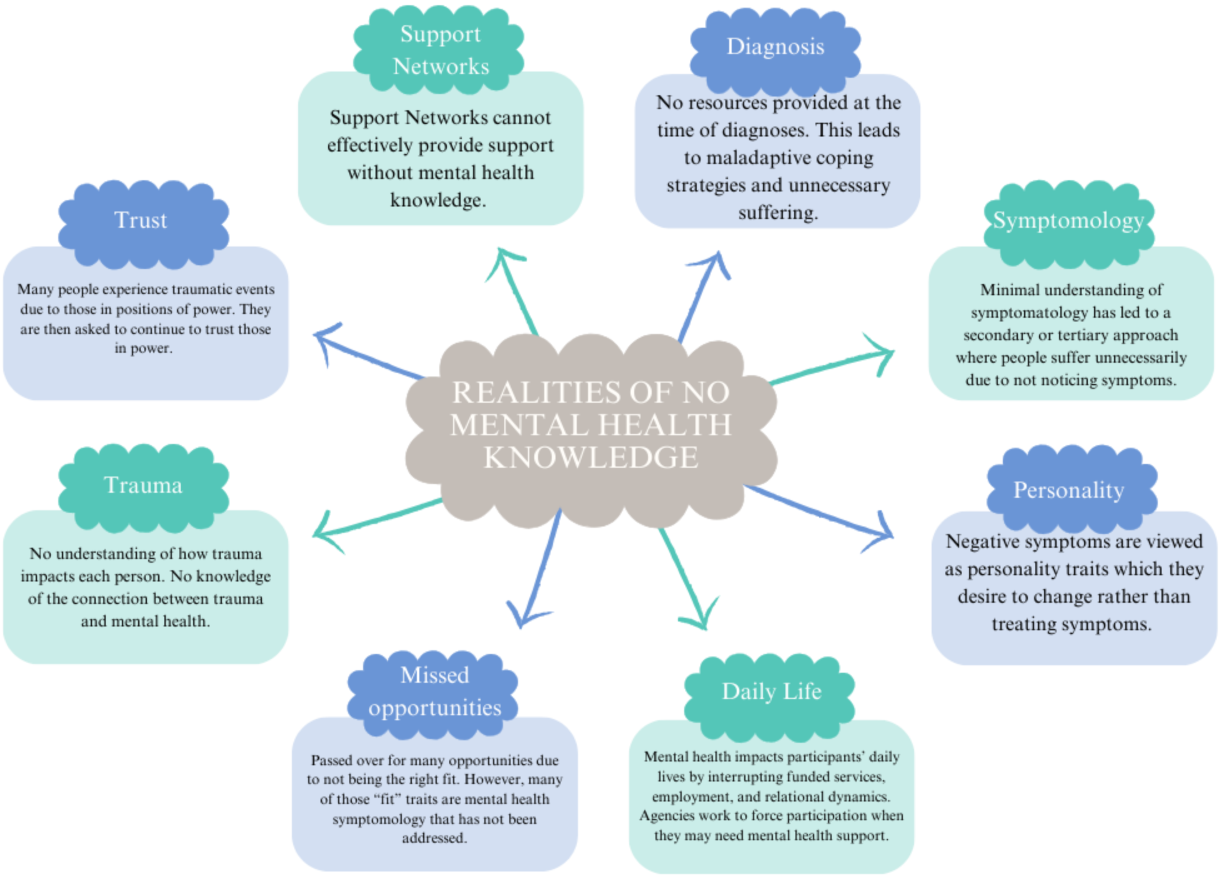
Limited Mental Health Understanding

The most significant gap in understanding was the participants' understanding of their own mental health. This reality links us back to the systemic oppression and institutionalized discrimination that a person with an IDD experiences on a daily level. Many participants who were experiencing mental health symptomology were seen by DDMH. Through DDMH, they received either an official diagnosis, a suspected diagnosis, and almost always medication to combat the symptomology they were experiencing. However, zero education for the participant or their support networks accompanied the diagnosis. Only one of the nine participants could easily identify their symptomology without prompting. Every other participant noted aspects of themselves, like sadness, suicidal ideation, angry outbursts, or manic episodes, without connecting them to their mental health diagnosis. Instead, they noted these behaviours as negative aspects about themselves that they wanted to change. However, no one had the tools or resources to work towards that desired change because there was no mental health support or education happening. When discussing the consistent theme of systemic oppression, the lack of knowledge being offered to individuals with IDD is by far one of the most impactful pieces. If we are gatekeeping access to knowledge for those who can only understand it at a certain level, we are limiting an entire group of people from being able to learn and develop new skills. We are also limiting a person's ability to cope with the struggles of mental health, which keeps them stuck without any option to learn new coping skills.

Figure 6 highlights the realities that many participants experienced due to having no mental health knowledge. This information was collected directly from the results and the literature review. The impacts of this are compounded when assessing the layers of oppression a person may experience when multiple pieces impact a person's daily life. Also, many of the identified factors often overlap for individuals with IDD. Additionally, new findings are also highlighted, such as negative mental health symptomology being viewed as personality traits, missed opportunities many participants experienced due to negative mental health symptomology, or the dynamic of trust in support networks when, for some participants, they have had extremely negative experiences.

Figure 6

Realities of a Person Having No Mental Health Knowledge



Support Network

A person's support network is one of the most determining factors in the participant's overall well-being. If the participant had even one person in their life supporting them to advocate for their needs, that participant had significantly more access to services than those who did not. Tyler noted that when he was really down, his sister called his favourite staff from his day program and arranged for him to receive some one-on-one support. Tyler stated, “The staff came over and went for a walk with me; I told her about the situation, and after, I went up to my sister and said, I’m sorry and hugged her, and then we were on the same page again.” Kathy noted that her support network had been with her through so much; she also noted that sometimes she needs someone to talk things through with, stating, “We all probably need somebody to talk to for stress to get it out quickly.” Just sometimes I just need it out and then can figure out how to fix things.” For Tyler and Kathy, having a person to talk to about life stressors greatly impacted their ability to process whatever was going on in their lives at that moment.

With the importance of support networks being highlighted, it is imperative to note as well that, for the most part, many people in support networks are not effectively trained in mental health. Literature highlights that the responsibility for well-being often falls on the support network of the person with an IDD (Reynolds et al., 2018). As support networks work within a system full of institutional discrimination, this can often cause burnout, frustration, and hopelessness (Beighton & Wills., 2018). With that background in mind, a trauma-informed training approach is imperative to the individuals being supported and the support networks providing that support. Support networks are often full of extremely dedicated people who want to support a person to the best of their abilities. However, with limited access to resources, no training opportunities, and no therapeutic support for the person they are supporting, this creates an impossible situation for people in the support networks.

New Findings

Many of the results were consistent with the literature. However, some features that emerged within the global themes were noted that also expanded on the current understanding of the experiences of individuals with IDD who are experiencing mental health symptoms.

Specifically, these supplementary features include the embodiment of systemic oppression, the complications with self-advocacy in a system that guards information, diversity that compounds oppression, and language barriers many people with IDDs experience. These dynamic pieces hold people with IDDs in positions of powerlessness in a system that promotes independence and self-advocacy. However, without the resources and tools, this promotion becomes unjust.

The Embodiment of Systemic Oppression

Systemic oppression has been evident throughout the results and discussion. The fact that so many people have experienced mental health symptomology and have never been given access to resources, counselling, or scaffolding of understanding of symptomology makes it clear that the priority for government funders is not for the well-being of individuals with IDD but rather the minimization of symptomology and maintaining the status quo. Systemic oppression is not a far-removed theory. It is an everyday reality for individuals living with IDD who are experiencing mental health symptomology. The systemic oppression is also made clear in the approach to mental health services that are in contradiction with research, lack of trauma-informed training for individuals and support systems, and significant lack of resources.

The minimal funding offered for mental health services creates one of the most significant barriers for people to access the support they need to improve their mental well-being. If all a person is being provided is medication without any information about themselves, their symptoms and what to watch for, it paralyzes the person in a system where they are only reliant on pharmaceuticals rather than utilizing an approach that combines both medication and therapeutic intervention. This observation highlights the focus on cost over a person's mental health. It is simply easier and, at that moment, less expensive to keep increasing medication than it is to develop resources and create funding for a person to seek mental health support.

However, this approach keeps a person locked in a system that creates reliance and dependency rather than creating freedom and self-advocacy.

DDMH Advertised Services. There is an ongoing scenario where, if you look at DDMH's selection of services offered, you will assume that if a person is struggling with their mental health and has an IDD, they would likely be able to receive access to these services. However, it is more common that they are not offered at all. All participants from this study and the members of the focus group at the beginning of the study were never provided any therapeutic services that were advertised. These observations fit with my consultations with several professionals working in the field and with my own 15 years of experience in the field. I have never worked with anyone who has received DDMH services outside of a quick assessment and medication prescription. The fact that a government agency would advertise counselling services to offer hope to struggling families and rarely provide them is unjust. This also perpetuates the cycle of embodied systemic oppression in that it keeps families reliant on government agencies when they do not offer full services for people who need them.

The Problem with Self-Advocacy. Many individuals with IDD consider themselves self-advocates, they speak up for themselves, advocate for their needs, and make their opinions known. Many self-advocates and their support networks have worked tirelessly to create space for their voices to be heard. That has come with a lot of resistance. Within the disability community, there has been a big push to continue focusing on self-advocacy and independence, which in many areas is phenomenal. However, when we look at the landscape of disability services for mental health, we can see a huge missing piece of the puzzle. How can we expect individuals with IDD to advocate for themselves if the system is gatekeeping information on mental health and how to best take care of ourselves? Self-advocacy primarily thrives in environments that have scaffolded information into plain language, created accessible resources for all people, and developed a system where communication and questions are welcomed. In our current system, we are setting individuals up for failure if we are asking them to advocate for themselves in a system that is fundamentally created to keep them out.

Amongst the participants, mental health knowledge was missing, the connection of their life experiences and how they process the world around them was not there, most could not name their common symptomology, and several did not know the difference between a registered clinical counsellor and the managers at their day services. The majority of participants also stated that mental health did not impact their day-to-day lives; however, when asked more detailed questions, it was very clear that their daily symptomology was impacting most areas of their lives. However, because no context was ever provided for their mental health symptomology, that connection was never made. The expectation that self-advocates should begin to speak up for their rights in the mental health space is vastly behind due to no one ever providing information in an accessible format for people when they are diagnosed with a mental health disorder. Or they were never providing trauma-informed training to support networks on how to support a person when they are experiencing mental health symptomology.

Compounded Systemic Oppression

At times, many individuals spoke about additional barriers in their lives that have impacted their abilities to access mental health resources. Several people noted that their support networks were not advocating very strongly on their behalf for mental health resources. As stated, support network training is an ongoing issue. It is solely up to the support network if they would like to investigate mental health resources for the person they are supporting. However, the reality is that this creates an unfair disadvantage for the person looking to access services whose caregivers are not advocating for them. Additionally, due to minimal funding, many individuals with IDD are living off very little financially. Coupled with the compound struggles of a person with a disability diagnosed with a mental health disorder, it is incredibly challenging for that person to find outside employment to make more money. With that, most individuals with IDD cannot afford to pay for therapeutic services privately. The fact is that when we start to compound the systemic oppression a person with a disability may be experiencing, the barriers to services continue to grow.

Language Barriers

The way each of us speaks about life is familiar to us and our circle of people. At work, school, or other areas, we may speak differently about topics than we would if we were discussing something with a close friend. The unspoken tensions, sarcasm, or inside jokes can create a barrier between us and another person in the room. This is the reality for many people with IDD. How we speak can often confuse and create a dynamic where they may feel like outsiders to a meaningful conversation.

At times, when we speak more professionally, we may use unnecessarily complex language to highlight a level of professionalism that may otherwise not be communicated. However, this, too, can create a barrier for many individuals with IDD. This phenomenon is not because individuals with IDD are not intelligent; often, it is because they have yet to be given exposure to many types of conversations. Often, for individuals with IDD, complex conversations happen about them or around them but typically do not include them. Due to that, many discussions about mental health for individuals with IDD may not feel relatable or understandable and many caregivers may lack experiences or examples of clear communication strategies.

As many individuals with IDD approach a medical system, the language often used in these situations is often not very accessible to many people. So, what little bit of information is being given is often described in a way that can be highly challenging for any person to understand. Additionally, information is rarely given in plain language format. So even when information is attempting to be passed along, often, it is in a format that is not understandable to the client that the professional is serving. We are inadvertently creating more barriers to services that could ever be needed.

One interview question explicitly asked if their mental health impacted their daily life. Multiple participants initially stated that their mental health did not impact their lives. However, when the question was broken down to specifically ask about the impacts on their day program, employment, or home life, almost all indicated that, in fact, their mental health did impact their lives. This highlights that if we are asking questions and assuming the person fully understands the question, we are likely not getting an accurate answer about their symptomology, mental health status, and its impacts. However, when we take the time to break down a question into plain language, we will likely receive more thorough information about the individual with an IDD. With that, the creation of mental health resources in plain language is imperative to the support of individuals with IDD.

Suggested Strategies for Change

Incremental Improvement

Looking at our current system, there are many pieces that would benefit from substantial change. Government-funded systems are often slower to change, with created barriers in place to keep current systems of power steady. Understanding that change will likely be slow however every inch of improvement towards better care is worth the fight. This thesis began with laying the foundation of change that has taken place over the last fifty years. This history is encouraging over that time frame. It is important to note that while we are not where we want to be, change is possible. It is also more realistic to recommend changes offered in smaller pieces. This discussion highlights three critical changes in our current system that would help move mental health services forward.

Trauma-Informed Mental Health Support

As we have established, currently, there is almost no mental health education for both the individual receiving a diagnosis as well as for the support network walking alongside the individual with an IDD. One of the best ways to support a person through a new experience is if there is a foundation of understanding trauma-informed mental health practices. Trauma-informed practices view distress responses as an unmet emotional need (Williamson & Qureshi, 2015). Rather than looking at every perceived negative behaviour as bad, a trauma-informed lens views it as information about a need, this need is often for safety, emotional needs, choice, empowerment, or collaboration (Keesler et al., 2023). The trauma-informed approach moves away from the medical and behavioural intervention model as it views people as fully human with unique needs. This view also creates a holistic approach that considers a person's symptomology as genuine needs rather than a negative outcome that needs to be changed.

To implement a trauma-informed approach, support network training is essential to ensure that the daily practices align with the ideology of trauma-informed care (Keesler et al., 2023). Increased funding by CLBC and other government-funded agencies must be provided to develop trauma-informed training for all support networks. A new government policy is not sufficient in this case. Rather, increased funding and the creation of trauma-informed training are essential. Many agencies that provide direct support work tirelessly to ensure that individuals are supported well. However, research highlights that when the onus is solely on agencies to create, develop, and implement these trainings without any expertise or funding, the efforts are often not effective (Keesler et al., 2023).

With that, the increased funding for this initiative would be put into training programs focusing on the fundamentals of a trauma-informed approach. These trainings can inform support networks on how to support a person with an IDD through a trauma-informed lens. These trainings would also highlight what mental health support through a trauma-informed lens would look like and the best ways to support someone who is struggling with mental health symptomology. A trauma-informed lens differs from the current behavioural intervention approach in that the focus is less on the behaviour the person is exhibiting and more on the motivations behind the behaviour. However, it has been proven effective and has positive results when assessing the overall well-being of individuals with IDDs (Keesler et al., 2023). Finally, it is essential to note that this is just the first step in creating trauma-informed care, the transformation towards this lens is the beginning of change, not the end.

Plain Language Resources

Many individuals with IDD have a reading comprehension that may be lower than average. This is a known reality across all government funders and agencies providing support. However, it is uncommon for resources to be provided to individuals with IDD in a plain language format. When a person is diagnosed with bipolar disorder, no resources are given to them that they can comprehend independently. Due to that, another significant change would be to create a wide range of plain language resources for mental health diagnoses to be provided to agencies and through the medical system. The purpose would be that when a person is diagnosed with a mental health disorder, they can take home information and can ask for help when needed.

These resources could go over the basics of a mental health diagnosis, common symptoms, typical types of medications, risks and benefits of medication, and who to talk to when they are struggling. Each of these listed areas was identified throughout the results as an area in which the participants needed more information. Plain language resources could continue the process of breaking down barriers and preventing the gatekeeping of knowledge that should be accessible to everyone. It should be a fundamental human right to have access to resources and education when you are being diagnosed with a mental health disorder.

Increased Funding for Individual and Group Therapy

By now, it should be clear that the number of traumatic events that individuals with IDD face throughout their lifetimes is unacceptable. It should also be clear that the current standards of care and support are inadequate to support individuals with IDD to process those experiences. The clear connections between individuals experiencing trauma and a potential mental health diagnosis are also prominent. And yet, systemic oppression is still evident in the funding model that continues to medicate rather than allow a person the opportunity to process their experiences.

A goal that understandably may take more time is the increased funding for individuals with IDD to receive individual and group therapeutic support. If the standard of care for those without disabilities is medication in conjunction with therapy, it is unjust that we do not offer that same support for individuals with an IDD. The expectation for individuals with IDD to not be impacted by these increased traumatic events speaks to the institutionalized discrimination and systemic oppression that many people face daily.

Additionally, the importance of group therapy cannot be overlooked. Many individuals with IDD often report feeling isolated, compounded with mental health, the level of othering they may experience is astronomical. Group therapy creates togetherness and strong relationality will create an environment where many may feel more comfortable speaking about their experiences, feeling supported, and learning from each other. CLBC must increase the funding to enhance the well-being of individuals with IDD. To deny them the right to therapy would continue this cycle of oppression that focuses on quick fixes.

Future Research

Limitations

Several limitations were noted throughout this project. First, due to the systemic barriers that were in place, some participants struggled at times to identify the specific support they received for their mental health. When appropriate, some participant's support networks were asked to confirm specific answers to ensure clarity. However, that missing knowledge around mental health was at times layered into impacting the participant’s responses to the interview questions. Second, this study consisted of nine participants. If time and financial restraints were removed, a study with more participants would be beneficial to strengthen the transferability of results. Finally, although questions were reviewed by a self-advocacy committee to ensure readability in plain language, in the interviews with the participants, at times, some struggled to understand the questions without prompting. While this was always done in a way that did not lead to the answer, this can be considered a limitation.

Future Research

Future research is imperative for individuals with IDD. Research cannot stop with just the knowledge that mental health resources are needed without increasing research on the best ways to support individuals with IDD. Suggestions for future research are to create more studies on the impacts of therapeutic support on mental health symptoms for individuals with IDD. There are numerous studies on the rates and effects of trauma and mental health for those with IDD, but that is often where the research stops. Developing studies that are dedicated to the best ways to approach therapeutic resources and support individuals with IDD is imperative.

Another topic of future research is assessing what therapeutic modalities are most effective when working with individuals with IDD. Therapy cannot be approached in a one-size-fits-all manner; instead, resources need to go into studies that better understand therapeutic approaches for individuals with IDD.

Further, the hope would be that through this research, better training for counsellors would become available. More training is needed for those studying to become therapists; with these studies, the hope would be that more counsellors would utilize that information in their own practices, and more individuals with IDD could receive therapy. Research would also be essential to understand a counsellor's hesitation to learn about individuals with IDD and the barriers they may have encountered in wanting to learn and understand this population. As we increase funding and support for individuals with IDD, counsellors must also be informed and educated when working with this group.

Finally, future research may also investigate trauma-informed training for support networks and how that may impact the daily support for individuals with IDD. As noted, support networks make a fundamental difference in the type of support a person receives. Understanding how utilizing a trauma-informed approach would impact not only the individuals with IDD but also the support networks could support this work further.

Conclusion

Individuals with IDD experience systemic oppression daily. The trauma and adverse life events statistics are staggering, and the research highlights that this leads to increased vulnerability to mental health disorders. Through a strengths-based and trauma-informed approach to research, nine interviews were completed, and a thorough analysis of the data highlighted four critical themes that impact the daily lives of those with IDD. The results found a focus on a quick-fix approach that focuses on the minimization of symptoms so individuals with IDD can function acceptably within their funded programs. A quick fix does not view the person as a complex being who needs the opportunity to process their experiences and to strengthen their coping resources. Caregiver support was instrumental in the well-being of individuals with IDD; however, support networks received minimal resources and training to best support individuals with IDD facing real life challenges. Many participants struggled with their general and personal knowledge of their mental health, even though they are working hard to flourish in their lives which highlights the injustice that many people experience.

The results also highlighted needed changes within the current funding system. CLBC and agencies providing direct support must implement trauma-informed practices at every level. Trauma-informed training will aid in understanding individuals with IDD and minimize re-traumatization. It will also ensure that support networks are trained and provide effective support to individuals with an IDD. Additionally, plain language resources must be developed to spread knowledge and awareness about trauma, mental health diagnoses, symptomology, and when and how to ask for help. Government funders and agencies must provide accessible support which individuals with IDD can access independently and learn more about their own mental health. Finally, increased funding for therapeutic support is imperative to the overall well-being of individuals with IDD. Both individual and group therapy resources could support individuals with IDD to process their experiences while also providing a sense of community and understanding. If the focus is on providing the most realistic support possible for those with IDD, government funders, families, and allies must increase support for individuals with IDD to process the high number of traumatic events they experience. Mental health support should not be a privilege, it needs to be accessible to all people.

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APPENDIX A: Glossary

Term	**Definition**
Asymmetric Relationships	Unequal power relationships between people in a relationship.
Community Living B.C. (CLBC)	Government body in B.C. that provide funding for individuals who are diagnosed with an intellectual or developmental disability or who have need diagnosed with autism spectrum disorder.
Community Living Agencies	Provide the direct support with the funds provided by CLBC.
Individualism	A view where identity primarily focuses on one person's individual view of themselves and does not rely on others.
Intellectual or Developmental Disability (IDD)	A person who has been diagnosed with an intellectual or developmental disability as per the DSM-5-TR
Intersectionality	Intersectionality describes the merging or intersection of multiple marginalized identities. See Appendix B.
Primary Prevention	Focuses on support that prevents symptomology. Often intervening before health effects occur.
Representation Agreement	A representative to help make decisions, or make decisions on behalf of the adult, with respect to personal care and health care, the routine management of financial affairs

	obtaining legal services for the adult and instructing counsel.
Secondary Prevention	Focuses on support once symptomology begins and intervention to support recovery.
Self-Advocacy Group	These are groups of individuals with IDD who can advocate independently and pursue various advocacy and accessibility projects within agencies and the community
Strong Relationality	A view that acknowledges that humans are relational beings that rely on each other to thrive. Relationships are viewed and instrumental and mutually beneficial to flourishing.
Support Network	Family member, caregiver, friend, or support worker. A person that the individual with an IDD trusts.
Support Worker	Often contracted or employed by community living agencies and work directly with individuals with IDD in various capacities.
Tertiary Prevention	Provides support once in a mental health crisis. Recovery is often longer.
Trauma-Informed	This focus acknowledges the need to understand a person’s life experiences in order to deliver effective support.

APPENDIX B: Intersectionality Visual

Intersectional Identities and Disability

This graphic was supported by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0005).

APPENDIX C: Invitation Email/Script

Note: The following sample illustrates the content for invitations to participate in this the research wording and other details may vary in different situations

Hi (Insert name),
My name is Melissa Kramer, and I am currently in my second year of Trinity Western University's counselling psychology program. I am conducting a study on the lived experiences of adults who are neurodiverse or have a developmental disability with their experiences with mental health disorders. As part of my study, I am interested in interviewing individuals who have been diagnosed with neurodiversity or with a developmental disability through Community Living British Columbia (CLBC). Additionally, participants in this study must have experienced mental health symptoms.

I am looking for six to eight participants who have the following characteristics:
- Diagnosed with either neurodiversity, such as autism, developmental disability, or other diagnoses, such as fetal alcohol syndrome and receive support through (CLBC).
- Have experienced mental health symptoms
- Can Self-Advocate
- Can communicate in English. Alternate forms of communication are welcome.
- Willing to participate in a 1–2-hour long interview either in person, over the phone, or through Zoom.

If you have any questions, please let me know.

Warmly,

Melissa Kramer

APPENDIX D: Consent Form

Experience of Adults with Disabilities and Mental Health

Principal Investigator: Melissa Kramer, MA Counselling Psychology Student, Department of Counselling Psychology, Trinity Western University

Faculty Supervisor: Marvin McDonald, Ph.D., Associate Professor, Department of Counselling Psychology, Trinity Western University

Purpose: The purpose of this study is to understand individuals with intellectual or developmental disabilities (IDD) and their experiences with a mental health diagnosis. Historically, many individuals with IDD have experienced significant adverse life events, which can lead to a mental health diagnosis. The aim is to understand from the individual with an IDD their direct experience and to capture what was offered, what that experience was like for them, and if they were offered any therapeutic support.

Procedures: This study involves 3 hours of participants time, including a 1-2 hour long interview, intake, and debriefing. You will be asked to share your experience in receiving a mental health diagnosis. The study will focus on when the participant began experiencing symptomology, what it was like to ask and receive help, and what support was offered to them. A brief background history will also be collected.

Potential Risks and Discomforts: There are minimal risks associated with this research; however, participants will be asked to share personal experiences that may cause some discomfort to talk about. If you are uncomfortable at any point during the interview, you have the right to stop the interview and wait until you are ready to continue.

Confidentiality: Any information that is obtained in connection with this study and that can identify you in public will remain confidential and will be disclosed only with your permission or as required by law. Interviews that are video-recorded and transcribed by the principal researcher will be stored on an encrypted drive under the pseudonym that the research participant has chosen. Only the principal researcher and her supervisor will listen to the audio recordings. The transcripts will not include identifying information, and only members of the research team will have access to the written documents. Once the project is completed, all recordings will be destroyed, and written transcripts will be kept on an encrypted drive for future research.

Contact for information about the study: If you have any questions or desire further information with respect to this study, you may contact Melissa by email at mkramerresearch@gmail.com or her supervisor, Marvin, at mcdonal@twu.ca

Contact for concerns about the rights of research participants: If you have any concerns about your treatment or rights as a research participant, you may contact the Ethics Compliance Officer in the Office of Research, Trinity Western University, at 604-513-2167 or HREB@twu.ca.

Consent: Your participation in this study is entirely voluntary, and you may refuse to participate or withdraw from the study at any time without consequence. Withdrawing your participation will not affect relations between you, myself, and members of the research team. If you wish to end your participation and have your responses withdrawn, please contact Melissa by email at, phone at, or in person. Please keep in mind that you will not be able to withdraw your information after final data analysis procedures have begun, and your responses have been incorporated into themes in the study; however, your anonymity will be maintained throughout the study through the use of your provided pseudonym.

Signatures Your signature below indicates that you have had your questions about the study answered to your satisfaction and have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study and that your responses may be put in an anonymous form and kept for further use after the completion of this study.

____ ________________________
Research Participant Signature Date

____

Printed Name of the Research Participant signing above

APPENDIX E: Consent Form in Plain Language

Experience of Adults with Disabilities and Mental Health

Who is completing the research project: Melissa Kramer, MA Counselling Psychology Student, Department of Counselling Psychology, Trinity Western University

Supervisor: Marvin McDonald, MA Ph.D., Associate Professor, Department of Counselling Psychology, Trinity Western University

Goal: The main goal of this research project is to have a better understanding of individuals with IDD and their experiences when having mental health symptoms. Historically, many people with IDD experience increased levels of challenging life experiences that can often lead to mental health symptoms (depression, anxiety, etc.). The hope is to speak directly with individuals with IDD to hear from them about their first-hand experiences and what support was offered at that time.

How we will gather the information: The study will include one 1-2 hour long interview. This can also be broken down into smaller meetings if needed or desired. The interview will focus on when the participant began noticing mental health symptoms, what it was like to ask and receive help, and what types of support were offered.

Potential Risks and Discomfort: There are very few risks in this type of research project. At times, participants will be asked to share personal experiences that may cause some emotional discomfort. If the participant is uncomfortable at any point and would like to stop the interview, that is okay. Participants will be reminded of this at the beginning of the interview.

Confidentiality (How we ensure your information is kept private): All information gathered in this project will be kept private and will only be shared with the participant's permission or if required by law. All interviews and related materials, such as recordings, transcriptions, or notes, will be kept on an encrypted USB. An encrypted USB is a USB that is password protected. Only the researcher and supervisor will listen to or watch the recordings. The transcripts, which are the written words that were said in the interview, will contain no information that would be identifying. Once the project is complete, all recordings will be erased, and all data gathered will be kept safe on an encrypted USB for future research.

Who can you contact if you have a question? If you have any questions or would like further information with respect to this study, you may contact Melissa by email at mkramerresearch@gmail.com or her supervisor, Marvin, at mcdonal@twu.ca.

Who can you contact if you have a question about your rights as a research participant? If you have any concerns about your treatment or rights as a research participant, you may contact the Ethics Compliance Officer in the Office of Research, Trinity Western University, at 604-513-2167 or HREB@twu.ca.

Consent: Participation in this study is completely voluntary and you may choose to not participate or withdraw from the study at any time without consequences. If you wish to end your participation, please contact Melissa as soon as possible by email at, phone at, or in person. Please be aware, that you will not be able to withdraw your information after final analysis procedures have been completed and your responses have been incorporated into themes in this study. However, your privacy will be kept throughout by using a pseudonym. A pseudonym is a fake name that will be used throughout.

If during the interview we notice you are having a hard time and may need support after the interview, please list a contact person you give us permission to call.
Support person name: ________
Phony number: _____________

Signing your name: By signing your name, this says that your questions about the study have been answered to your satisfaction. You are saying that you consent to participate in this study and that your responses may be put in an anonymous form and kept for further use after the completion of this study. You are also saying that you have received a copy of this consent form for your own records.

____ ________________________
Research Participant Signature Date

____

Printed Name of the Research Participant signing above

APPENDIX F: Screening Interview

Interview Guide

Note: The following sample illustrates the content for screening interviews for potential participants. The wording and other details may vary in different situations.

Introduction: *Thank you so much for taking the time to speak with me to see if you would be a good fit for the study! I am going to ask you a few questions, if you need any further explanation, please do not hesitate to ask. If you do not feel comfortable answering some of the questions, please just let me know. You are also welcome to stop the interview at any time if you need to.*

No matter if your background fits this project or not, I will let you know in a few days. I am glad to talk more with you about this project and any questions you might have.

Screening Questions

1. Are you diagnosed as having a developmental disability or neurodivergence?
    a. Do you receive support through CLBC?
    b. How would you like me to refer to your developmental disability? (ex. person with a disability, disabled/neurodiverse person)
2. Do you feel comfortable talking about your developmental disability/neurodivergence?
    a. What concerns/worries do you have in talking about your experience?
3. Do you consider yourself a Self-Advocate?
    a. Are you comfortable speaking up for yourself and your needs?
4. Can you tell me how you spend your days?
    a. What are the things you enjoy most about your days?
5. In your life, have you ever experienced mental health symptoms?
    a. Can you explain what that was like for you?
    b. In the last 6 months, have you experienced any psychosis symptoms?
6. Do you feel comfortable talking about your mental health and your experiences?

a. What concerns/worries do you have in talking about your experience?

Thank You: *Thank you so much for your time, I will be in touch in the next few days to either schedule an interview or let you know if you are not a good fit for this study and why.*

APPENDIX G: Interview Questions

Note: The following sample illustrates the content for screening interviews for potential participants. The wording and other details may vary in different situations.

Introduction Script: *Thank you so much for taking the time to participate in this study. Before we begin, I want to remind you that you can choose to share as much or as little as you want, and if, at any point, you feel uncomfortable, please let me know. You are also welcome to request further clarification for questions.*

I also just wanted to note that there are no right or wrong answers, but how you remember your experiences and what you felt in those moments is important to this study.

Interview Guide

1. Is there a pseudonym (fake name) you would like me to utilize for you?
2. Can you explain/describe to me how you spend your days? What kinds of things do you usually do?
3. Tell me what you do to advocate for yourself.
    a. Have you always felt able to speak for yourself? Would you like to share an example of when you spoke up for yourself?
    b. Were there any limitations holding you back from advocating for yourself?
4. Can you explain your experience in having mental health symptoms? What was that experience like for you?
    a. What did having mental health symptoms look like for you?
    b. Can you explain to me the types of thoughts that were running through your mind when you began having symptoms?
    c. How did you know it was time to tell someone?
    d. Who else in your life noticed that you were having mental health symptoms?
    e. Did any of these symptoms impact your day-to-day life?

5. When you sought help, what resources were offered to you?
   a. Did you feel that the offered resources were helpful?
   b. Can you explain if you felt heard/understood by the doctor/specialist?
6. Tell me about when the doctors or your support person was discussing the diagnosis with you, Were your previous challenging life events ever discussed or considered?
7. Was counselling ever suggested as an option? If so, what resources to connect with a counsellor were offered?
8. In what ways did these experiences/symptoms interfere with your employment/day service?
9. Was a behavioural interventionist brought in to support you through that experience?
10. Do you still receive any support for your mental health?
11. Is there anything else about your experience that you would like noted?

Exit Script: *Thank you so much for your time, I truly appreciate your responses. I will be in touch with the results of the study once it is completed.*

APPENDIX H: Recruitment Poster

RESEARCH PARTICIPANTS NEEDED

WE ARE CONDUCTING A STUDY ON FIRST-HAND EXPERIENCES OF THOSE WHO ARE NEURODIVERSE AND/OR HAVE A DEVELOPMENTAL DISABILITY AND THEIR EXPERIENCES WITH MENTAL HEALTH.

Requirements to Participate

Diagnosed with either neurodiversity, such as autism, developmental disability, or other diagnoses, such as fetal alcohol syndrome and receive support through Community Living B.C.

Have experienced a mental health symptoms.

Can Self-Advocate

Can communicate in English; alternate forms of communication are welcome

Compensation

All participants will receive a $25 gift card to a place of their choice as a Thank-You for their time.

If you think you're a fit, contact:

[redacted]