

**Mental Health and Intellectual Disability:**

**The Experiences of Disability Support Workers in Relation to the Mental Health Needs of  
Clients**

A Thesis Submitted to the  
College of Graduate Studies and Research  
in Partial Fulfillment of the Requirements  
for the Degree of Master of Education  
in the Department of Educational Psychology  
and Special Education  
University of Saskatchewan  
Saskatoon

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## **Abstract**

Adults with intellectual disabilities are known to have a high prevalence of mental health problems. As with other Canadians, access to adequate mental health services for this group is a challenge. As a result, these individuals along with their family members are turning to intellectual disability services for assistance with issues of mental health regardless of the fact that employees do not receive specialized training in this area. Research indicates that intellectual disability service providers play an important role in the mental health of these individuals, are supporting service users with a variety of mental health issues, and are in need of specialized training. What is missing from this research, is the experience, of Canadian support workers as they support the mental health of adults with intellectual disabilities. Through the use of a general qualitative research design, this study attempted to explore and understand the experiences of direct support workers as they support adults with intellectual disabilities where issues of mental health and well-being appear. A semi-structured interview was utilized to elicit descriptions of these experiences in addition to the perceptions of direct support workers in relation to training competencies and needs. It is anticipated that through understanding the experiences and perceptions of direct support workers, a better service model can be delineated.

## Acknowledgments

I believe that no journey in life is as successful or as full-filling without the guidance of those around you. I would like to extend thanks to several people who provided me with both support and inspiration along the way.

First, thank you to my supervisor Dr. Tim Claypool for recognizing the importance of this topic, guiding me through the process, offering feedback and encouragement when needed, and providing articles and texts that helped with the development of this project.

Thank you to my committee members: Dr. Beverley Brenna-for your kindness, encouragement, feedback, and especially all your grammar corrections that plagued my writing. I appreciate how all your comments and questions inspired me to see how this project could be so much bigger than I initially considered it to be. Dr. Vicki Squires-for your questions and comments which pushed me to make this project better, and for making me contemplate the definition of mental health and how it is discussed in our society. Thank you both for helping me with this accomplishment.

To the University of Saskatchewan for the Graduate Scholarship which assisted to help pay for this journey.

To the participants of this study for volunteering to so openly discuss their experiences and perspectives. Without you this project would be nothing.

Thank you to my former colleagues as well, who experiences inspired this project in the first place.

An extremely special thank you to my parents, Phil and Dianne Thiemann for providing me with a constant supply of support, self-esteem boost, and recognition and acceptance that I will likely never stop going to school no matter how many times I claim that I will. Dad-without your rational and calming presence I would never have gotten to where I am, so I thank you. Thank you, Joey, for always raging when I rage. It helped more than you know!

Finally, to my Kris for always being supportive, patient, pushing me when I hated everything, listening when I needed it most, and having more confidence in me and my abilities than I could ever have in myself. I am eternally grateful!

## **Dedication**

I would like to dedicate this thesis to all of the individuals that I have had the pleasure of supporting and working with over the years. Thank you for being who you are, persevering every day, inspiring me to work towards being a better person, and allowing me into your lives. Your friendships have filled my heart and shaped my future.

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# Mental Health and Well-Being: The Experiences of Direct Support Workers in Supporting Adults with Intellectual Disabilities through Mental Health Issues

## Chapter 1: Introduction

Access to adequate mental health services is an issue faced by many individuals within Canadian society (Canadian Mental Health Association, 2012). Adults with intellectual disabilities are no exception. This vulnerable population is often highly reliant on family members, caregivers, and paid support workers for assistance in many facets of their lives, including mental health. As care for these individuals moves more into the community realm (Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007), this population is turning to community based support organizations to get their mental health needs met in the absence of access through more traditional means. Many of these organizations and their employees are becoming the sole means of support for the mental health and well-being of participants in their programs (Lunsky et al., 2007). This support is being provided daily despite a lack of specialized training and guidance in mental health disorders and appropriate standards of care (Rose, O'Brien, & Rose, 2007).

### My Experience

As a direct support worker (DSW) for a community organization that provides vocational day programming for adults with intellectual disabilities (ID), I have witnessed how the mental health issues of adults with ID can interfere with their ability to do their job within a supported employment environment which in turn interferes with my ability to do my job. Although I received thorough training in crisis management I experienced many moments of feeling incompetent, feeling confused, feeling heartbroken, and feeling scared that I did not have the skills to support the individuals that I worked with through their moments of mental health crisis. Mental disorders and episodes of poor mental health can have detrimental effects on so many facets of people's lives, including employment and workplace participation. Society in general is beginning to recognize this and workplaces are starting to provide support to employees who need it (Government of Canada, 2016). Individuals with intellectual disabilities should be offered the same support through the people best able to provide it based on a greater understanding of client needs. This need for support may mean providing the DSWs and job

coaches who work with these employees with the competence and training to support their client's mental health and well-being.

During my years working as a DSW I experienced multiple instances where an individual I was supporting vocationally was experiencing issues of poor mental health or psychological distress. It was honestly a daily occurrence. Some days the issues were relatively minor while on others they were serious and had a wide ranging impact on the individual's life. There was one instance, however, that really made me think, impacted me greatly, and seriously made me question my ability to competently support vulnerable people with these types of issues. A couple of years into my work an individual who was long diagnosed with and receiving medical intervention for several psychological disorders began experiencing turmoil in his personal life. The care home within which he had been living for several years was closing due to the age and developing ill health of his caregiver. As you can imagine this was extremely unsettling, scary, and confusing for this individual. As a result of this distress the individual self-harmed causing fairly serious injury. Through discussions with the individual it came to light that he was also experiencing dissatisfaction at work which was exacerbating his distress. He didn't enjoy the jobs we had to offer him but also didn't want to not work.

When this information was disclosed to my colleagues and me, we all were shocked, concerned, and at a complete loss. I remember a colleague looking at me and stating, "So what are we supposed to do with that?" I had no idea what to tell her. I had no idea what to do to help him. As a job coach, we were there primarily to assist our clients with the vocational tasks they were assigned, help them learn and navigate workplace skills and etiquette, and encourage their participation in the community. We had no idea how to help someone experiencing such extreme psychological distress and dissatisfaction with life. I remember being determined to see to it that he had a good day but really all I could offer him was the job site I was attending that day, encouragement, and my presence as a person who cared. But I was on edge all day, constantly monitoring him for signs of distress, and likely more of a bother to him than any real reassurance. In addition, because I was so preoccupied with his well-being, the other individuals that I worked with that day lost out on supports that I would have normally provided them.

By the end of the day I was stressed and felt completely incompetent. I also felt a lack of confidence in my abilities that I had never felt before. It was then that I became determined to

figure out what we as DSWs and more specifically job coaches “could do with that” when faced with the information and instances where an individual we care about and support daily is faced with such psychological distress and helplessness. From that day, this project was born.

### **My Educational Background**

As I progressed through the courses required for the School and Counselling Program, I found that I was better able to competently listen, guide, and support the people I worked with when they experienced mental distress on the job. My newly developed counselling skills enabled me to actively listen, reflect, and assist clients working towards their own understanding of and solution to issues. The knowledge I gained of psychological disorders, symptoms, and effective interventions helped me to assess and approach situations in ways that were most helpful to the individual with whom I was working. Finally, an understanding of the cognitive processes underlying the way people think allowed me to approach each person with flexibility and guidance based on the client’s abilities as well as their needs.

The knowledge and skills that I have gained as a result of training in mental health and well-being has resulted in feelings of competency and confidence previously lacking. In turn, I now feel better able to do my job, support others to do theirs, and feel that I am a better well-rounded support to the intellectually disabled population. These experiences, in addition to concerns expressed by co-workers, led to my desire to further explore the experiences of fellow DSWs in supporting individuals through mental health issues during the course of providing support services to this population.

When someone you work with closely on a daily basis experiences the bereavement process or the heartbreak of unrequited love it is nearly impossible to ask them to put it aside and focus on the job at hand. This is true in any work environment and I would say it is even harder in a workplace where the individuals with whom you work already struggle on a regular basis to “fit in” to the community, to understand society’s nuances, and who rely heavily on paid carers for social and emotional support. As individuals with ID struggle to communicate their feelings, deal with stressful situations, and are particularly vulnerable to the development of mental health disorders, it is important that those whom they turn to for support be aware of the signs and symptoms of mental distress and feel competent in their abilities to assist them and refer them for further support as they work through their problems. Although mental health support may not be

the mandated purpose of a community based organization that serves the intellectually disabled population, DSWs are in a unique position to see what their clients may not be able to say, offer support through stressful life experiences, assist with the development of protective factors and skills, and prevent the further development of poor mental health.

## **The Present Study**

### **Purpose and Research Questions**

This study utilized a constructivist approach wherein phenomena are understood to be socially constructed through the subjective experiences of individuals (Hays & Singh, 2012). Such an approach supports the study's purpose of exploring and understanding the perspectives and experiences of direct support workers as they assist adults with intellectual disabilities through issues of mental health and well-being.

Through this understanding readers of this study may gain knowledge regarding the mental health issues individuals with ID are dealing with and how DSWs are supporting them with these problems. In addition, the information generated from this investigation may provide insight into areas where DSWs feel confident in their abilities while at the same time revealing areas for consideration in terms of supplementing current training practices. Both DSWs and the clients they serve can potentially benefit from the identification of these experiences. Increasing competence and confidence will ensure improved support practices. Therefore, this study investigated the following questions: (1) What are some of the personal and social challenges that adults with Intellectual Disabilities cope with during their everyday activities?; (2) How do direct support workers provide needed supports to adults with Intellectual Disabilities who experience mental health challenges?; and (3) To what extent are direct support workers prepared to ensure that the well-being and mental health of adults with intellectual disabilities is maintained?

### **Definition of Terms**

#### **Community Based Organizations (CBOs)**

For the purposes of this study, organizations offering services to adults with intellectual disabilities are defined as those community based organizations (CBOs) that are funded under

the Saskatchewan Ministry of Social Services mandate. According to the Government of Saskatchewan (2015) there are 85 not-for profit organizations which under the agreement with the Ministry offer services to approximately 3,900 people with intellectually disability (ID). These 3,900 individuals fall under the Rehabilitation Act definition of intellectual disability which states that intellectual disability is “a condition of arrested or incomplete development of mind whether arising from inherent causes or induced by disease or injury” (Government of Saskatchewan, 2015). Different researchers, countries, and regions within Canada interchangeably use labels such as intellectual disability, developmental disabilities, and learning disabilities (commonly used in the United Kingdom). As a result, reference will be made within this study to all of these terms.

### **Direct Service Workers (DSWs)**

The individuals who are employed by these organizations to provide services to these clients are generally referred to as direct (developmental or disability) support workers, under the acronym DSWs. They are employed to perform a wide variety of tasks as a means to support and assist individuals with ID with various aspects of their lives.

### **Mental Health**

The definition of mental health utilized by researchers is quite varied and complex but generally relies on a diagnosis of psychiatric disorder (Costello & Bouras, 2006). Some research however, indicates that the presence of life events can contribute to the mental health of individuals with ID in the same manner as the general population (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). In accordance with this research, DSW experiences supporting adults with ID with life events such as bereavement, dementia, social issues, medication side effects or any other issue that may interfere with a person’s mental health will be included for the purposes of this study in the definition of mental health issues in addition to the presence of psychiatric diagnosis.

## **Chapter 2: Literature Review**

The following chapter provides an overview of existing literature regarding intellectual disability in Canada, issues surrounding the mental health of this population, direct service workers' training, as well as the importance of DSWs to the mental well-being of individuals with ID. It is important to note that there was relatively little Canadian based research found within this area, and what there is has been based largely within the province of Ontario and focuses on issues of burnout, unpaid caregivers or family members, and problems within the medical system for individuals with ID. Therefore, much of the research literature presented here is from Europe and New Zealand.

### **Background to the Problem: Intellectual Disability and Mental Health**

#### **Intellectual Disability in Canada**

Intellectual disabilities (ID) are described in the DSM-V as impairments in general mental areas which interfere with adaptive functioning in the conceptual, social, and practical domains. These conditions emerge during the developmental period and are diagnosed based on the impact they have on the individual's adaptive functioning (American Psychiatric Association, 2013). In order to meet the DSM-V diagnostic criteria the individual must meet three requirements: (1) deficits in intellectual functioning such as, learning from experience, academic learning, problem solving, and abstract learning as measured through cognitive assessment; (2) deficits in at least one area of adaptive functioning resulting in an inability to fulfill socio-cultural and developmental standards for independence and social responsibility; (3) onset of deficits occurs during the developmental period (APA, 2013). In addition to these criteria, four specifiers (mild, moderate, severe, and profound) are included in diagnoses and are defined on the basis of adaptive functioning which reflects upon the level of supports the individual will require over their lifetime.

There are three different domains of adaptive functioning that can be impaired in an individual with ID: conceptual, social, and practical (APA, 2013). The conceptual domain, sometimes referred to as the academic domain, refers to the person's competence in reading, writing, arithmetic, memory, and problem solving, among others. The social domain is a reflection of the individual's interpersonal communication skills, empathy for others, and

friendship skills, as well as an awareness of others' thoughts, feelings, and experiences. Finally, the practical domain involves the person's ability to learn and self-manage across a variety of settings and includes personal care, money management, managing job responsibilities, organization, and behavioural regulation in addition to other skills (APA, 2013). Adaptive functioning can be influenced by a variety of factors including cognitive functioning, education, motivation, socialization, employment opportunity, medical condition, and mental disorder. As previously mentioned, an individual's skills and abilities within these domains are used to determine the level of personal supports required for the person (APA, 2013). The level of supports will also influence the level of skills required by those providing those supports.

Intellectual disability results from several genetic, environmental, mental, and physiological factors and may co-occur with several other mental, neuro-developmental, medical, and physical conditions (APA, 2013). Causes of ID may be prenatal (genetic syndromes, inborn errors of metabolism, brain malformations, environmental conditions); perinatal (variety of labour and delivery related events); and postnatal (traumatic brain injury, seizure disorders, infections, etc.) (APA, 2013). Due to the fact that IDs result from such a wide variety of causal factors, the presentation of impairments, behaviours, co-existing disabilities, needs, and required supports is extremely heterogeneous. This makes assessment, differential diagnosis, and the development and provision of adequate individualized support services a complicated endeavour.

### **Prevalence of ID and Issues of Mental Health**

The results of the Canadian Survey on Disability (CSD) that was conducted in 2012 by Statistics Canada indicated that 0.6% of Canadians adults aged 15 or older living within private dwellings report having a developmental disability (Disability in Canada: Initial findings from the Canadian Survey on Disability, 2015). The findings of this survey are consistent with estimates of prevalence rates found by researchers which indicate that approximately 1-3% of the population have some form of ID (Lunsky et al., 2007). Geographic information for all the provinces in Canada indicates that Saskatchewan has, at 0.9%, the highest rate of working-age people with intellectual disability (PALS, 2006).

In addition to the deficits in cognitive and academic functioning that occur as a result of ID, these individuals also experience extremely poor health that is characterized by higher rates



of mortality (Bittles et al., 2002; Ouellette-Kunz et al., 2005) and are at an increased risk of developing an additional psychiatric disorder (Ouellette-Kunz et al., 2005; Einfeld, Ellis & Emerson, 2011), which results in a dual disability (DD). Most studies indicate a prevalence of psychiatric disorder ranging from 10-40% of individuals with ID (Lunsky et al., 2007). Cooper et al. (2007) reported that a population-based study of adults with ID in Scotland found that of 1023 individuals 40.9% met diagnostic criteria for mental ill health including affective disorders (6.6%), psychosis (4.4%), and anxiety disorders (3.8%). Another study aimed at investigating the incidence of mental ill health amongst 651 adults with intellectual disabilities in the greater Glasgow area of the UK, found that over a period of two years' mental ill health occurred in 16.3% of the sample (Smiley et al., 2007). Even when problem behaviours were excluded, 82 individuals (12.6%) experienced an episode of mental ill health within that time frame. The findings of this research indicate that adults with intellectual disabilities may experience mental illness at a rate that is 3 to 4 times greater than the general population (Cooper et al., 2007).

There are few studies that look specifically at the prevalence of mental health disorders within the Canadian population of individuals with ID. A study from Manitoba however, found an increased prevalence of both dementia and depression in their population with developmental disability versus the population without developmental disability (Shooshtari, Martens, Burchill, Dik, & Naghipur, 2011). Specifically, younger adults (aged 20-54) with a developmental disability were at a four times higher risk for dementia and a three times higher risk for depression (Shooshtari et al., 2011). The co-existence of ID and a psychiatric disorder can have serious effects on a person's daily functioning by interfering with employment, education, relationships, and residential placement (NADD, 2016). Due to these issues, people with ID and a psychiatric disorder tend to spend a great deal of their time in the care of service providers and reliant on paid workers to provide assistance in various aspects of their lives.

### **Factors Leading to Increased Vulnerability**

The factors that lead individuals with ID to this increased vulnerability for mental health issues are very complex. Many of the mechanisms that affect this vulnerability are interrelated and interact, creating multifaceted pathways of susceptibility (Ouellette-Kunz et al., 2005). According to Trollor (2014) a wide variety of social, biological, and psychological risk factors lead to the high rates of mental disorders that are seen in this population. For instance, an

individual with ID may experience reduced opportunities to engage in various life choices, and may have restricted social networks, limited coping skills and greater susceptibility to stress which in turn increases vulnerability to psychological distress and mental illness. In addition, developmental brain abnormalities, pharmacological treatments and their side effects, as well as specific genetic conditions that are associated with ID can all influence a person's susceptibility to the development of a psychological disorder (Trollor, 2014).

Many specific factors related to mental health incidents experienced by people with ID have been found to be similar to those found in the general population. There are important differences however, as people with ID were more likely to have previous mental ill health; urinary incontinence; type of accommodation and support; more severe IDs; adult abuse; being fully mobile; childhood parental divorce; and preceding life events (Smiley et al., 2007). Smiley et al. (2007) pointed out that although some of these factors may be unchangeable they may help to identify those at greater vulnerability. In addition, many other factors related to incidence can be addressed through intervention and support. Of particular interest is the finding that individuals who were living in accommodations outside of their family home were found to experience higher rates of mental ill health incidents. Smiley et al. (2007) concluded that their results point out the need for paid carers to be trained in the detection of early warning signs of mental ill health, in screening programs, and in the effects of life events on this population.

Research into the correlates of mental ill health in the ID population highlights how exposure to multiple life events such as moving, bereavement, relationship issues, and employment problems may trigger psychopathological distress in this vulnerable population (Lunsky & Elserafi, 2011; Tsakanikos, Bouras, Costello, & Holt, 2007; Hastings, Hatton, Taylor, & Maddison, 2004). In addition, this population may in fact be more vulnerable to the impact of such events because they have a greater reliance on others as well as a reduced cognitive capacity to deal with stress and adjust to new situations (Martorell et al., 2009). In an investigation of the impact of life events on a sample of 281 men and women with ID referred for specialist mental health services in South-East London, Tsakanikos et al. (2007) found that exposure to a single life event was associated with depression, schizophrenia, personality disorder, and female gender. Exposure to multiple life events however, was correlated with adjustment reaction, personality disorders, and depression. Although causal links cannot be

drawn from this research the authors conclude that their results indicate an increased vulnerability to the effects of life events in people with ID (Tsakanikos et al., 2007). While this study was not exhaustive in terms of sample size or type of life event, it does highlight the negative effects that common life events can have on this population and that there is a need for these effects to be recognized by the individual's care staff such that appropriate support and intervention can be provided before the development of a psychological disorder occurs.

Traumatic life events have also been found to play a role in the development of mental ill health in this population. Martorell et al. (2009) found that 75% of the 177 individuals with mild to moderate intellectual disabilities in their sample had experienced at least one traumatic event during their life time, and 50% of them had experienced one in the previous 12 months. In addition, exposure to one or more traumatic events was found to significantly increase the odds of mental disorder. They suggested that for this population, traumatic experiences may act as predisposing factors to the development of a mental disorder while more general life events act as precipitating factors. This is important because prevention efforts are generally put in place when predisposing factors are known to exist (Martorell et al., 2009). In other words, adults with ID are highly likely to have experienced a traumatic event within their life time that puts them at a greater risk of developing a mental health disorder. They are in turn more vulnerable to and less able to deal with the stress that accompanies common life events triggering psychological distress and increasing their vulnerability even further. By being aware of this vulnerability and looking for symptoms of mental ill health, paid carers and staff are more competently able to provide increased psychological support for already vulnerable clients.

### **Barriers to Mental Health Services**

According to Lunskey et al. (2007), following the deinstitutionalization of the intellectually disabled population in Canada, a separation occurred between the provincial health services authorities and the authorities who oversee the provision of intellectual disability services. This resulted in an emphasis being placed on community care rather than the provision of specialized psychiatric services. Therefore, individuals with dual diagnosis are now forced to seek help from generalized mental health services that are not set up for ease of access for this population nor are they well-equipped to adequately deal with their unique needs and situations (Lunskey et al., 2007). In addition, although Canadians with disabilities are guaranteed, through

various laws and policies (Canadian Charter of Rights and Freedoms, provincial Mental Health Services Acts, and the ratification of The Convention of the Rights of Persons with Disabilities) the same rights and freedoms as all Canadian citizens, there exists no current national framework or committee to guide the provision of healthcare services for people with intellectual disabilities. As a result of these issues, the quality of mental health services depends upon the region within which the person lives, the expertise and funds that are available within that region, and the extent to which policy makers have recognized the unique needs of the ID population (Lunsky et al., 2007).

Lunsky et al. (2007) conducted a national survey wherein key informants from 10 provinces and 2 territories reported on the range of mental health services available to them as well as perceived gaps in that service provision. According to their findings the vast majority of respondents rated generic mental health service providers as inadequately equipped to meet the needs of children (56%), adolescents (62%), and adults (63%) with both intellectual disabilities and issues of mental health. In fact, mental health agencies, such as hospitals and community mental health centres, were the least frequently accessed services (31-55%) reported by the respondents of this survey. In contrast, these people were more likely to turn to intellectual services providers or the family physician in order to gain help with mental or behavioural issues. In addition, although specialized services were found within a few regions of the country, the waitlists for these services were on average 4 months or longer, and less than half of the respondents reported the existence of expert or specialized service availability within emergency room or inpatient treatment (Lunsky et al., 2007).

Although caregivers do their best to support individual with ID with mental health issues they are sometimes ill equipped to deal with the severity of problems and behaviours that can occur. Emergency rooms are often the place both paid and unpaid carers turn to in times of severe psychiatric crises (Weiss, Lunsky, Gracey, Canrinus, & Morris, 2009). According to an investigation of emergency department use by both paid and unpaid caregivers of adults with ID in Ontario, carers tend to bring the individuals they support to the ED when community services are deemed to be unavailable or all of their options have been exhausted. The vast majority of the individuals brought to the ED are repeat users indicating that they are not receiving adequate mental health care within the community (Weiss et al). The carers who participated in this study

pointed out several issues with the use of the emergency department in these situations including: wait times and insecure location of the ED, lack of knowledge of hospital staff, diagnostic overshadowing (symptoms or behaviors that may be due to a specific mental illness are attributed to another disorder), lack of time spent in assessment, over reliance on medication, and lack of respect shown to either patient or caregiver.

In addition to the experiences of caregivers, research has also investigated what barriers exist for general medical practitioners and mental health professionals as they attempt to provide health services to the ID population. For instance, general practitioners in Australia reported the existence of two main barriers which compromise the quality of health care that they can provide to patients with ID (Lennox, Diggins, & Ugoni, 1997). These two barriers, difficulties communicating with clients and problems obtaining complete patient histories, affect all stages of health care provision and make it extremely difficult to ensure that patients get the help they need. It is important to note that difficulties with communication often accompany an ID, and may be what make it most difficult to obtain patient history, ascertain the problem and its severity, determine baseline health/behaviour, and ensure intervention understanding and compliance (Lennox et al., 1997). The Lennox et al. (1997) study also found a range of other GP reported barriers to providing adequate medical services to patients with ID including: GP lack of training and experience, consultation time restraints, poor compliance to management plans, difficulties determining the problem, poor continuity of care, examination difficulties, and a lack of knowledge regarding available service and resources available to this population.

In addition to the solution of increased specialised ID training and experience for GPs, the practitioners who participated in the Lennox et al. (1997) study suggested that increased involvement of family and paid caregivers in the health care process would greatly assist with communication, ensure full disclosure of patient history, help with the identification of the problem and its severity, and support intervention compliance. Although this investigation has limited generalizability to the Canadian context it does highlight the importance of caregiver input into the provision of health care services to individuals with ID. By being aware of and communicating the symptoms, behaviours, side effects, and histories of the people they support DSW's can act as a tool to ensure that these individuals are receiving the health care they need (Lennox et al., 1997).

Of particular interest and importance are more recent research findings that indicate that the psychologists and psychiatrists who are responsible for the assessment, diagnosis, and provision of therapeutic interventions of individuals with ID and mental health disorders continue to be inadequately trained as well as inexperienced in the unique circumstances of this population. The Royal College of Psychiatry (2004) highlighted a report of 424 psychotherapists, psychologists, and psychiatrists in the UK who worked within learning disability services. They found that even when this population is able to access mental health services, a major barrier to receiving adequate and effective psychotherapy was actually the skills and training of the clinician. This report emphasized the need for clinicians to obtain specialist skills and training in intellectual disabilities issues, as well as for intellectual disability services staff to become familiar with issues of mental health in order to meet the therapeutic needs of their clients.

A lack of training has also been found within the Canadian context. In an investigation into psychology graduate training in the area of developmental disability, Weiss, Lunskey, and Morin (2010) found that while the majority of the 333 students surveyed felt training in developmental disability was important, they found it difficult to obtain suitable educational and experiential opportunities. Although many of the students indicated that they had been educated on how to diagnose developmental disabilities, at least half of the respondents had not been trained in any specific developmental disability topic. In addition, of those who had received training the level of coverage was quite often deemed inadequate (Weiss et al., 2010). This lack of training is important because within Canada it is these providers of general mental health services who will be assessing, diagnosing, and designing intervention plans for not only the developmental disability but also any co-occurring mental health disorders this individual will have.

## **Disability Support Workers in Canada**

### **Training and Employment**

Due to the fact that the provision of services to individuals with ID fall within the purview of each individual province there are no specific national standards of practice and/or guidelines for the training and minimal level of competence of practice for DSWs in Canada, although several organizations and associations across the country advocate for such standards

and guidelines (Ontario Association of Developmental Disabilities, 2016). As previously mentioned, organizations and individuals that serve this population must abide by the Human Rights Code of Canada and the provincial Mental Health Act, but each province does not necessarily have a specific document guiding professional staff in their daily activities (Lunsky et al., 2007). One exception is Ontario, as the Ontario Association of Developmental Disabilities published the Developmental Service Workers Standards of Practice in 2011. This document outlines five standards that are intended to describe the priorities, values, and practices of DSWs in the developmental services sector (OADD, 2011).

According to the document, its purpose is to “promote excellence in the DSW profession” (OADD, 2011). The five standards that outline the minimum level of practice that should be provided are: provision of service to service recipients, competence, integrity, confidentiality, and consent. Within each standard are several values as well as a framework from which DSWs can guide their behaviour to ensure ethical and appropriate provision of support services. It is important to note that although this document attempts to structure and professionalize the work done by DSWs in Ontario, it is not legally binding and only DSWs that are members of the OADD are asked to adhere to those standards (OADD, 2011). The professionalization of the community living services sector, as well as the development of minimal standards of competency and practice, are advocated by numerous associations and organizations throughout Canada. Behind this advocacy is the rationale that best practices and professional standards will enhance the lives of individuals with intellectual disabilities (OADD, 2016).

Although this has not always been the case in Canada, an internet search indicates that the vast majority of organizations that provide services for individuals with ID now require that their employees have post-secondary education in the form of either a university degree majoring in some aspect of social sciences, or a disability support worker or related certificate. The DSW certificate can be attained through the completion of a one year program offered by several educational institutions throughout Canada. These programs, such as the one offered by SaskPolytechnic located in Saskatchewan, are designed to develop knowledge and skills as well as offer direct practical experience in several key areas in order to provide respectful,

compassionate care for individuals with disabling conditions and complex needs (School of Human Services and Community Safety: Disability Support Worker Certificate, 2016).

According to the SaskPolytechnic School of Human Services and Community Safety overview of the DSW certificate program, the classes offered provide skills and competency in the areas of basic care; behavioural support and crisis prevention; disability support services; exceptionalities and human growth and development; interpersonal, professional and employability skills; person-centered planning; and quality of life enhancements (Saskatchewan Polytechnic, 2016). Although the descriptions of several classes included in the DSW program mention the importance of understanding multiple exceptionalities, person-centred principles, and crisis management, none directly mention the importance of mental health and well-being for these individuals. Nor do they explicitly state that they teach direct, practical skills required for assisting clients within this area.

In addition to the required courses, the DSW certificate program also places emphasis on and offers hands-on learning experience through the required two practica with community based residential or vocational-centre based agencies (Saskatchewan Polytechnic, 2016). According to the SaskPolytechnic program description, students develop their skills in providing basic care, planning programs, and implementing activities within environments that are safe, secure, and stimulating.

Finally, the SaskPolytechnic program recognizes that individuals learn in a variety of different ways and therefore offers students the opportunity for prior learning assessment and recognition (PLAR) (Saskatchewan Polytechnic, 2016). PLAR is a process wherein skills and knowledge attained through work experiences, non-formal training, etc. are identified, assessed, and recognized. The student has the opportunity through PLAR to challenge particular courses by demonstrating their knowledge and skills through either evidence or skill. The individual's demonstration is then evaluated by a SaskPolytechnic course content expert and it is determined whether the students' work experience, informal training, or other allows them to meet the requirements of the course and thereby be given credit. This process can be especially useful for those individuals who have been working within services for many years prior to the newly developed educational requirements of many disability service organizations.



In Canada, disability support workers (DSWs) are employed by various government and private organizations to provide a wide variety of intellectual disability services. These services can vary greatly but may take the form of personal care, supported employment, life management or residential caregiving. The roles and responsibilities of DSWs are extremely vast depending on their work environments. Also, variable is the in-house training provided within organizations. Regardless of the specific description of their employment or the training they receive, DSWs quite often end up acting as an agent of support for the mental well-being of individuals with ID (Lunsky et al., 2007). The national survey research conducted by Lunsky et al (2007) indicated that 75% of respondents (clinical specialists, ID researchers, advocates/family, service providers, and policy makers) turned to an intellectual disability service agency when someone with an ID had a behavioral or mental health issue. This is despite the fact that employees of these agencies do not necessarily receive any formal training in the areas surrounding mental health issues (Rose, O'Brien, & Rose, 2007).

### **The Importance of ID Service Providers**

Social support acts as an important protective factor in preventing the development of mental problems and also contributes to quality of life (Lippold & Burns, 2011). Individuals with ID however often struggle to form and maintain the relationships necessary for social support (Lippold & Burns, 2011). This continues despite increased community presence and inclusion. Lippold and Burns (2011) compared the social and functional networks of a group of 30 individuals with mild ID with a group of 17 people with physical disabilities. They found that while adults with ID tend to engage in more activities within the community they have more restricted social networks. In other words, family members and paid carers tend to provide adults with ID with the vast majority of their social support. Paid staff were reported as being the most frequent providers (53.1%) of functional support including practical aid and emotional support. Although the sample size of this study restricts its generalizability, it does highlight the important role service providers play in protecting the mental health of individuals with ID.

In a review of the current literature detailing the issues surrounding the assessment of mental health problems in people with ID, Costello and Bouras (2006) concluded that alternative assessment measures are required in addition to traditional psychiatric tools when assessing this population for issues of mental health. Costello and Bouras (2006) argued that service providers

or “carers” are imperative in the diagnosis of mental health problems of individuals with ID. Quite often these individuals have limited communication skills which results in difficulty expressing their mental health problems. According to Costello and Bouras (2006) “carers” who spend extended amounts of time with an individual within a wide variety of environments are in the best position to develop knowledge of the person’s repertoire of behaviours and recognize when changes in pattern are occurring. It is these changes that indicate the onset of mental health issues in individuals who have difficulty expressing details about their own mental health (Costello & Bouras, 2006).

Based on their review, Costello and Bouras (2006) concluded that carers play a vital role in the detection of issues, form a bridge between individuals with ID, their family and other care staff, and may be essential to treatment implementation and follow-up. Due to the important role they play in detecting possible mental health issues it is imperative that DSWs be exposed to training initiatives aimed at increasing their ability to recognize signs of mental illness and make informed decisions regarding the importance of these signs (Costello & Bouras, 2006). By exploring the types of experiences DSWs are having, CBO’s will be in a better position to tailor these training initiatives to the training needs of their staff.

### **Experiences of Service Providers**

Several studies conducted in Australia, Ireland and the United Kingdom have reported on the experiences and training requirements of direct support workers when dealing with specific mental health issues of service users. For instance, Donley, Chan, and Webber (2011) examined the knowledge and experiences of support workers regarding the use of psychotropic medication. Although respondents reported that they felt competent in their abilities to support people with a disability who display challenging behaviors, they also felt they required more information regarding chemical restraints and the side effects of psychotropic medications. Although the use of chemical restraint is not used as often as it previously was, numerous adults with intellectual disabilities are prescribed medications to control the symptoms of mental disorders (Donley et al., 2011). It is conceivable that DSWs should have an awareness of these medications as well as their side effects if they are to adequately support individuals out in the community.

McEvoy, Guerin, Dodd, and Hillery (2010) investigated staff experiences of supporting adults with intellectual disabilities through the process of loss and bereavement. The

bereavement process can negatively impact mental health and it is highly likely that support workers will have to support clients through this process (McEvoy et al., 2010). The findings of this study indicate that these individuals experience loss and grief in much the same way as the general population, and quite often turn to staff to gain emotional support and understanding. The respondents expressed a need for formal procedures and training in the bereavement process as they were often relying on their own experiences and judgment. In addition, a number of the staff reported that assisting service users through experiences of loss had an impact on their own emotional well-being (McEvoy et al., 2010). These results indicate a desire by DSWs for formal procedures to deal with the mental well-being of adults with intellectual disabilities, as well as the possibility that supporting individuals through these types of issues has the potential to affect the mental health of support workers.

### **Effectiveness of Training**

Research has been conducted which reported on the effectiveness of mental health training and workshops on care staffs' awareness, knowledge, and feelings of competence concerning the mental health and well-being of service users. According to Mohr, Phillips, Curran and Rymill (2002) staff members of ID services in Australia are lacking in knowledge and expertise in dual disability, which is a term used to describe individuals who have an intellectual disability as well as a concurrent psychiatric disorder. Mohr et al. (2002) provided training to a group of ID service staff and mental health staff regarding dual disability in order to determine its effectiveness in increasing knowledge, confidence, and collaboration. They found that the training program increased confidence in working with individuals with DD, increased knowledge of DD, produced positive changes in work practices, and increased commitment to collaboration.

Costello, Bouras, and Davis (2006) conducted a pre-post study in South East London to measure the effectiveness of an introductory training workshop in increasing care staff awareness of mental health issues. The participants in this study consisted of 66 care staff within the intervention group who were compared to a comparison group of 65 care staff who received no training. Prior to intervention 77% of the intervention group and 83% of the comparison group reported that they had no previous training in mental health issues. The intervention utilized in this study aimed at increasing care staff awareness and understanding of mental health issues and

needs. This study found significant improvements in staff awareness and knowledge of mental health issues following training, and these changes were maintained 4 months after intervention. Costello et al. (2006) concluded that the training workshop utilized within their research was a reflection of current resources and could be easily adopted by service agencies to improve the training of care staff who work with individuals with ID. By offering training in mental health issues and needs service, agencies can equip their staff with the competence to offer the mental health assistance required by adults with ID.

### **Summary**

Adults with intellectual disabilities are an extremely vulnerable population in our society. As the services that support these individuals continue to move toward greater community involvement and as these individuals continue to turn to these service agencies when experiencing mental health issues, it is essential that we gain an understanding of how direct support workers experience these moments when support is sought, the issues with which they are assisting, as well as their perceived competencies and needs regarding training on mental health and well-being. DSWs are in a unique position to provide protective social support, assess and detect signs of mental ill health and distress, and act with advocacy and positive support in the promotion of mental health. Through the provision of training, DSWs can become increasingly aware, competent, and confident in their ability to assist adults with ID to be mentally healthy.

### **Present Study**

This descriptive qualitative study will increase understanding of the experiences of DSWs, lead to insight into the mental health and well-being of adults with intellectual disabilities, and inform training programs for service providers. Its significance lies in the fact that through understanding of experience we can ensure better practice and protection of the vulnerable in society. This study will fill this gap in the literature by seeking to explore and understand Canadian DWSs perceptions and experiences of providing mental health support to adults with ID.

### **Chapter 3: Methodology**

The following chapter provides the methodology that was used for the current study. It begins with a discussion of qualitative research within the constructivist paradigm, which is followed by a brief summary of Merriam's (2002) basic interpretive qualitative research approach. Following this will be a presentation of the procedures for participant recruitment, data collection, and analysis. Finally, the chapter will end with a consideration of issues regarding ethics and trustworthiness.

#### **Qualitative Research**

Qualitative research is a broad and varied approach used to study the complexity and intricacies of human phenomena (Marshall & Rossman, 2016). Although qualitative research encompasses a wide variety of methodologies, there are some commonalities that exist. Qualitative research takes place within the natural world, it is interpretive in nature, focuses on context, is evolving as well as emergent, and pulls from multiple methods which demonstrate respect for the humanity of its participants (Marshall & Rossman, 2016). Qualitative researchers generally view the world and the social phenomena that occurs within it as complex and holistic. They systematically reflect and remain sensitive to their own identities and how they influence and shape the study (Rossman & Rallis, 2003). In addition, qualitative researchers utilize systematic inquiry and reasoning that is complex, multifaceted, and iterative (Marshall & Rossman, 2016).

Finally, qualitative research is often based on the understanding that meaning is constructed socially by individuals as they interact with the world and reality is not a fixed and measurable phenomenon (Merriam, 2002). This assumption is representative of the constructivist paradigm, which posits that knowledge occurs through the interactions of people, and that knowledge is then co-constructed and interpreted (Haverkamp & Young, 2007). Based on this paradigm, the researcher is recognized to play an important role in the process of developing knowledge and understanding. As such, I performed a critical role as I used my own experiences and perceptions in the process of understanding and interpreting the findings of this study.

## **Basic Interpretive Qualitative Research**

Due to the exploratory nature of the current study, Merriam's (2002) basic interpretive qualitative research design was utilized. Basic interpretive qualitative research emphasizes several characteristics including: an emphasis on understanding the meaning of a phenomenon, the researcher as the primary instrument of data collection and analysis, data analysis as inductive, and the reported outcome of that analysis as rich and descriptive (Merriam, 2002). This study incorporated all of these elements.

As the researcher, I was the primary instrument of both data collection and analysis. I had no prior hypothesis regarding the perceptions and experiences of DSWs or the outcomes of this study. In addition, the research process was inductive, in that all the data that I collected was used to generate and determine the thematic categories, rather than utilizing pre-determined categories (Patton, 2002). Finally, the ultimate purpose of the study is to explore the experiences of DSWs supporting adults with intellectual disabilities through issues of mental health, what they perceive their competencies to be, and areas/skills in which they think they need further training. This methodology allowed for clear description of a phenomenon with minimal interpretation required on the part of the researcher (Sandelowski, 2000). According to Sandelowski (2000) the aim of basic interpretive qualitative research is to attain full description of an event in the language of that event. Due to the fact that so little is currently known about the experiences of DSWs as they support adults with ID with their mental health, a basic interpretive qualitative methodology allowed for as thick and in-depth an exploration and description as possible.

## **Procedures**

### **Participants**

Following ethics approval from the University of Saskatchewan Research Ethics Board, five respondents were recruited through advertisement within Community Based Organizations (CBOs) that offer support to adults with intellectual disabilities within the province of Saskatchewan (see Appendix A). Permission to advertise was obtained from CBO management prior to advertisement. All respondents participated voluntarily, and their identities as well as the names of the organizations they work for were kept confidential. The participants were

provided with an informed consent package detailing study information, their rights as a participant, confidentiality, and requesting consent for the audio recording of the interviews (see Appendix B) (Rose et al., 2007). Informed consent is an ongoing process throughout research and as such the primary researcher ensured throughout the investigation that participants were aware of their rights. If they choose, all participants and organizations will be informed of the study results in order to ensure accountability to the community affected by the findings, and so the organizations can use the information regarding training needs as it sees fit (Hays & Singh, 2012).

The identification of gatekeepers and key informants was necessary as a means to gain permission to advertise the study within the organization, and to encourage participation. In addition, key informants within the organization were utilized in order to gain additional insight into the dynamics of the organization, clarification of organizational language, as well as any other important information that may have added additional substance to the investigation.

Participants were selected through purposeful sampling in order to ensure that they were both knowledgeable and informative (McMillan & Schumacher, 2010). A snowball sampling strategy was also utilized because potential participants were encouraged to pass on information regarding the study to other qualified individuals (Marshall, & Rossman, 2011). Participants were included based on the following criteria: at least three-plus months working with adults with intellectual disabilities, three-plus months working with a fairly consistent set of service users, and at least one experience providing support to an adult with ID experiencing issues affecting mental health.

### **Data Collection Strategies**

Individual semi-structured in-depth interviews were used to generate the data. The semi-structured interview was selected in order to allow the participants the freedom to fully discuss their experiences while also ensuring that the main purpose and questions sought by the research were addressed. In addition, the purpose of the in-depth interview was to ensure that a thick description of the phenomenon was obtained. Each interview session was approximately one hour in length. A preliminary interview guide (see Appendix C) was constructed and is based on the questions used in the Rose et al. (2007) investigation into the attitudes and knowledge of

service providers towards working with adults with learning disabilities and difficulties with mental health.

For individuals located within Saskatoon and surrounding area they were provided the freedom to choose the setting for which the consent and interview could take place. They were encouraged to choose a private location wherein they felt comfortable and issues of confidentiality could be easily addressed. Individuals located outside the city of Saskatoon and immediate surrounding area were provided the option of having the consent and interview be conducted over the telephone in order to ease travel concerns that were raised during recruitment. The transcript consent and release process was conducted via email at the request of all participants in order to ensure ease and convenience for them.

The interviews were audio recorded and then transcribed in their entirety. In addition, field notes were made during the interviews detailing frequently used words, phrases, and other statements that required follow up (Fredheim, Haavet, Danbolt, Kjongsberg, & Lien, 2013). When possible I used probes as a means to clarify participant responses as they occurred in the interview. Participants were asked to review the transcripts and field notes in order to ensure accuracy and validity (Hays & Singh, 2012). The participants then signed a data release form allowing for the use of the transcripts in the analysis and write up. During the consent process, the participants were informed that they had the right to withdraw their participation in this project and any data collected from them, up until the point in time that all the data had been pooled.

## **Data Analysis**

Thematic analysis was used as the method to identify, analyze, and report the themes or patterns within the DSWs experiences, types of mental issues they were assisting with, competencies they perceived that helped them with the situation, and areas of training they felt would help in the future. Thematic analysis is a flexible approach that allows the data set to be minimally organized while still providing rich detail (Braun & Clarke, 2006). The data was analyzed to identify recurring themes that occur across the data producing a rich and descriptive account of the findings (Merriam, 2002). An inductive approach to thematic analysis was used such that the process of coding was done without trying to fit the data into a pre-existing coding



frame or the researchers preconceived notions of the phenomenon (Braun & Clarke, 2006). Therefore, data analysis was reflexive and data driven.

The analysis process within qualitative research occurs concurrent to data collection, beginning when the researcher notices and makes note of issues of potential interest and patterns of meaning. According to Braun and Clarke (2006) there are several phases to thematic analysis and these phases were followed during data analysis for this study as they fit the purpose of the research. These phases are: (1) familiarization with data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. This process is not meant to be linear in fashion and as the data is analysed the researcher will move back and forth throughout the phases based on what the data reveals (Braun & Clarke, 2006).

In order to ensure accuracy of the themes and codes named during analysis there was potential for the respondents to be contacted for further follow-up and expansion of detail (Hays & Singh, 2012). Direct respondent quotations do appear within the written report in order to demonstrate the themes discovered during analysis. All respondents were made aware of this, consented to having their words used, and care was taken to make sure that individuals would not be recognized based upon their quotes. The transcripts from the interviews were reviewed, the data from each interview was compared to the other interviews, and thematic categories that were common across all participants were identified. These categories were then reviewed and smaller themes within each category were then identified and highlighted through the use of colored markers. From there each theme was reviewed and relevant quotations were marked with the use of colored tabs.

### **Trustworthiness**

The trustworthiness of a qualitative study is based upon the criteria utilized by the reader to determine whether the results found by the researcher are believable (Marshall & Rossman, 2016). There are however, several universal criteria that can be used to determine the trustworthiness of any qualitative research study. These include: social validity, subjectivity and reflexivity, adequacy of data, and adequacy of interpretation (Morrow, 2005). These criteria were considered and several strategies were utilized to increase trustworthiness throughout the course of this study.

## **Social Validity**

Social validity is a reference to how relevant the study is to current society. According to Morrow (2005) if a study is not applicable to the current social climate then the purpose for conducting that study is questionable. The current study is relevant and valid; as individuals with ID become increasingly included within society and the community, it is important that the people who work directly with them are able to support them with all their needs and goals. The health and social support of all Canadian citizens is important to our society. Therefore, if this study can provide insight into the mental health and well-being of this vulnerable population, it will be of value.

## **Subjectivity and Reflexivity**

The inherent nature of the data we gather and the processes that we engage in as qualitative researchers requires an acknowledgment of subjectivity (Morrow, 2005). From the constructivist perspective, as a researcher I act as an integral co-creator of meaning (Morrow, 2005). It was thus imperative that I make my assumptions and biases known and I utilized reflexivity to become more self-aware of unacknowledged biases and assumptions as they emerged during the research process. In addition, I also ensured that the reality of the data that I presented is that of the participants and not my own. Field notes were used by the researcher throughout the investigative process as a means to record non-verbal behaviours, language clarifications, thoughts, biases, and findings as they occurred throughout the study. Field notes allow the research process to be as transparent as possible, and add to the study's credibility and confirmability.

## **Adequacy of Data**

Adequacy of data is reflected in several factors but essentially requires that there be adequate amounts of evidence, a variety of different kinds of evidence, that interpretation is contextual and reflective of the culture of the participants, and consideration be given to both disconfirming evidence and discrepant instances of the phenomenon (Morrow, 2005). Simultaneous data collection and analysis took place in order to make sure that information was not missed or went unclarified. Due to the emergent nature of qualitative inquiry it is important that data be collected and analysed at the same time in order to allow for changes in questions,

method, and data sources as the data deem necessary (Hays & Singh, 2012). This strategy allowed this study to demonstrate credibility, confirmability, and authenticity. In addition, the use of field notes allowed for the recording of observations and jot notes to be made which provided for multiple sources of data.

### **Adequacy of Interpretation**

It is extremely important that the interpretation of the data be an accurate reflection of the phenomenon as it occurs within that particular context. Morrow (2005) suggested that in order to ensure adequacy of interpretation, full immersion in the data is required during data analysis, interpretation, and presentation. Repeated review of the transcripts, interview tapes, and field notes took place in order to ensure that a deep understanding of the data occurred. Planning is also important, and it was my intention to utilize a method of data analysis that allowed for themes to emerge as the data was collected. In addition, my interpretation of the data was balanced by the actual words of the participants of the study such that the presentation of research findings is a transparent reflection of their reality.

Member checking also occurred at various points throughout the research process. Member checking provides the participants with the opportunity to approve aspects of the interpretation of data that they provided to the researcher (Carlson, 2010). Respondents of this study were asked to review the transcripts of the interviews, the researcher's field notes, and themes as they emerge, in order to check for accuracy and validity. Member checking ensured that the findings of this investigation were a true reflection of the DSW experiences as they supported adults with ID with their mental health. Member checking improved the study's authenticity and confirmability.

Finally, it was the intention of the researcher that the qualitative report of the current study's findings be a thick description or detailed account of the research process and outcome. This addressed several additional criteria for trustworthiness including: transferability, authenticity, coherence, and substantive validation (Hays & Singh, 2012).

### **Researcher Self Reflection**

As a qualitative researcher, it is important to recognize and be transparent about how my own background and experiences have affected the research choices that I have made. My

personal experiences and context will influence my interpretation and understanding of this phenomenon.

My experiences working for a local CBO and offering job coaching and support to adults with ID are what led me to choose this research topic. Working with this specific population has become extremely important to me, and I feel that providing them with well-rounded support and skills is essential to their full inclusion and participation within society. In addition, as a student of psychology I have come to recognize the importance of mental health and well-being to the lives of everyone, as well as the negative influence that mental disorder can have on all aspects of people's lives. Individuals with ID are no exception to this, and in fact may be more vulnerable to these negative impacts. Full participation and citizenship is more than simple physical opportunity and presence; individuals with ID must also be provided with the support and skills required for mental health.

Based on these experiences, it is my assumption that other DSWs working within CBOs in Saskatchewan are assisting service users with a wide range of mental health issues and therefore qualitative descriptive research design is warranted in order to produce a comprehensive summary of their unique, daily experiences (Sandelowski, 2000). In addition, based on personal employment experience as a DSW it is assumed that the participants of this study will express a need for specialized training regarding mental health issues and how to competently support adults with ID with these issues. It is predicted that the experiences of DSWs will be a reflection of the mental health issues and needs of adults with intellectual disabilities, and insight will be gained into how best to support these individuals within the community.

### **Ethical Considerations**

Ethics approval was sought from the University of Saskatchewan's research ethics board. Issues surrounding informed consent, freedom to withdraw, and confidentiality were addressed and adhered to. Pseudonyms were assigned to all participants in order to ensure confidentiality. The importance of CBO client confidentiality was also stressed and maintained. Informed consent was an ongoing process to ensure understanding and continued desire to participate. In addition, the process of member checks was also detailed upon initial meeting in order to ensure understanding. Contact information was provided to all participants in case they had questions

regarding the research study, and in recognition of their time a \$10 gift card was offered to them. Finally, the data attained from this study will be stored at the University of Saskatchewan for a period of five years after which it will be destroyed.

## **Chapter 4: Results**

The chapter's overarching goal is to report the main findings of this qualitative research study, beginning with a general overview of participant information and followed by a presentation of the thematic findings. While all participants were assigned a pseudonym to protect their privacy, several of their direct quotations were included verbatim in this chapter, apart from filler words such as "like", "right", and "you know" that were edited out during the transcription process. This chapter concludes with a summary of some of the more germane findings that served to formulate recommendations detailed in the last chapter.

### **Participants**

There were five participants in this study. All the participants were female and they were assigned the pseudonyms Sarah, Tiffany, Amber, Julie, and Brandi. The fact that they were all female is not unusual given the high female to male ratio of individuals employed within this sector. They ranged in age from 23 to 46 years old. Three of the participants, Sarah, Tiffany, and Amber, work at group homes for adults with ID located within small towns in Saskatchewan. Within these group homes they provide a variety of personal, social and practical supports to the residents. Julie works with adults with ID within a vocational or workplace environment located in a small city in the province, and provides job coaching, employment support, and personal supports. Finally, Brandi works for an organization located within Saskatoon which provides educational, personal, and advocacy supports to individuals with Fetal Alcohol Spectrum Disorder (FASD).

The participants had various educational and training backgrounds. At the time of this study, Sarah, Julie, and Brandi all had bachelor of arts degrees in psychology. In addition, Brandi had returned to university to attain a degree in Education. Tiffany and Amber stated that they had no formal education and all their training was received through the agencies that they work for or through the pursuit of personal professional development. Therefore, this was a diverse group of individuals who related a broad variety of experiences. Participants located outside of Saskatoon were provided the opportunity to participate in telephone interviews. All four of them chose to participate in this manner. Brandi was interviewed in-person at her choice of location within Saskatoon. All five of the participants participated in semi-structured interviews followed by email discussions of and approval of the transcripts of those interviews.

The interviews took place between August and October 2016. Recruitment began in early August and was completed by mid-September 2016. The response was overwhelming as numerous organizations and individuals expressed support for the project. Each participant expressed their eagerness to share their experiences, and their belief in the importance of the topic for both DSWs and those they support. All the participants appeared to be open, honest, and transparent. They each expressed a desire to be kept informed regarding the status of the study and that they were excited to contribute to this research project.

### **Themes**

The five volunteer participants' descriptions of supporting adults with ID with issues of mental health were analyzed thematically. Three broad thematic categories which aligned with the study's research questions were identified. These categories included challenges, strategies, and developing competency. Within these broad categories three specific themes were further identified. Within the category of challenges the themes that emerged were primary and secondary disabilities, access to adequate supports, and staffing issues. The category of strategies contains the themes relationship, empowerment, and meeting them where they're at. Within the category of developing competency, the themes identified included holistic client knowledge, mentorship, and ongoing professional development. Finally, a last finding was identified that focused on ineffective strategies for supporting adults with ID with issues of mental health.

#### **Thematic Category 1: Unique Challenges Common among DSWs**

No job comes without challenges and this is especially true when your sole responsibility is supporting other people with their own daily life challenges. The five participants of this study highlighted several aspects of their work that they believed to be challenging for both themselves and those with whom they work.

**Theme 1: Primary and Secondary Disabilities.** The participants of this study reported a wide range of challenges that their clients and they themselves face during their daily activities. Julie said "I'm basically in a room with 20 to 30 adults of varying disabilities, so on a daily basis we can be dealing with any sort of physical and mental issues many times over." Julie went on to state:

The challenges can be anything from they didn't have breakfast so they are hungry to somebody passed away or is sick. Or another care worker moved...To breakdowns where you are just trying to figure out what is wrong. So, it could be something minor or it could be something fairly serious.

Sarah, Tiffany, and Amber all emphasized the communication and social challenges that often accompany primary disabilities as being highly prevalent and troublesome for those they work with. Sarah stated that the most obvious challenge for herself and her clients is "just a disparity in communication...learning how to communicate effectively with each individual". Tiffany and Amber, who work in the same group home, recognized that the individuals that they support really struggle with being social and understanding social cues. Amber stated "some of my participants don't know how to be social. They were brought up in institutions so they don't know how to be social." Tiffany relayed the following story as an example of how one client struggles in social situations:

We were out for a walk and saw a couple that I know, and stopped to talk. Every once in awhile I would kinda burst out in laughter and same with these other two people. I noticed that she would too but it was totally at the wrong time. After awhile I realised that she just wants to do what we're doing but she has no idea when to do it so she just does it cause she hears us do it. And that's pretty much what she does is echo what other people are saying. It just doesn't fit when she does it.

In addition to these challenges which are largely a reflection of the individuals' primary disability and/or life situation, all five participants also report that a large proportion of their clientele have also been diagnosed with a mental health disorder or secondary disability. In fact, the co-occurrence of a mental health disorder and ID is viewed as being quite normal. Amber stated "they all got a mental health disorder. It seems to go on par." Some of the diagnosed disorders mentioned by the participants included: depression, anxiety, Post-traumatic Stress Disorder (PTSD), and Obsessive-Compulsive Disorder (OCD). Brandi, who works with individuals with FASD and their caregivers provided a detailed description of her clients' struggles in this area:

The secondary disabilities include a realm of mental health concerns. Definitely I would say including, depression, anxiety is high. When you're feeling something inside and



you don't have a way to express it externally through your words or through behaviours, or what you're expressing doesn't match how you feel, that can cause a lot of angst in individuals...So, mental health concerns that I have with some of my clients include things like bipolar, schizophrenia, paranoia, and then substance use issues as well.

**Theme 2: Direct Access to Adequate Supports.** The second significant challenge reported by several of the DSWs interviewed was difficulty accessing and attaining adequate mental health services for their clients. Tiffany expressed frustration with the amount of medications that most of the individuals that she supports are on to deal with their various symptoms and disorders. She stated:

I understand that they need to be [on medication], but I think even the leadership is quite frustrated with the medical system trying to get the right dosages of certain medications and how they are interacting with others. I think that's a very frustrating aspect of the work.

Amber echoed this frustration with the medical system with this story of a client's visit to the psychiatrist:

One of them sees a psychiatrist once every three months, and they go in there and [ask] have you had any incidents? And of course, this one [says] no. So, then they're like okay she's good. And it's like no she's not! She had three [incidents] just on the way here!

Amber provided several similar stories and went on to state that there is a lack of communication as well as respect between those in the medical profession, those who make decisions about client well-being, and those who support them daily. She stated "nobody asks the support staff...that's the frustrating part."

Brandi also expressed that accessing services was challenging for her clients, especially when they are needed in a timely fashion. Brandi said "one of the struggles is actually finding supports that are available, and then waiting for the incredibly long wait list or call backs from people." She went on to express that long wait times for appointments or call backs from services are especially troublesome for individuals with memory impairments such as those often found in individuals with FASD:

It just falls through the cracks because chances are the person with FASD forgot that an appointment was made, or they forget to call back themselves. It's tough when someone says okay well you need to call us back because of the memory impairments and troubles with FASD. Often times that follow through doesn't happen. Because the client forgets. Or they thought they did when they didn't. They misunderstood. I thought they were going to call me back. So, I would say that part, making the connection can be really hard.

Brandi went on to state that she wished mental health services and professionals would provide her clients with brutal honesty and realistic expectations: "when you are calling someone the professionals need to be actually as brutally honest as they can be. If someone is not going to be able to see you for three months, don't say we'll call you right back."

**Theme 3: Ongoing Staff-related Issues.** The final challenge emphasized by several of the participants of this study was staffing issues. Staffing issues include a low staff to client ratio, a lack of adequately trained staff available to hire from, and discrepancy between approaches of staff as they support clients. Julie expressed that the number of participants per staff member was a real challenge at her organization which limits her ability to offer the one-to-one support required to build relationships. Julie stated "I would love to just sit down with each of them for five minutes...ask them so what are you doing? But you can't. And then you only seem to deal with the crisis's that come."

Tiffany and Amber raised the challenge of working for an organization that operates in rural areas within the province. Since the group home that they work in is located within a small town which is a significant distance from a major city, the pool of employees from which leadership can draw from is limited. As Amber put it, "There's no staff to pull from around here. No one wants to drive all the way out here to work. So, you kinda gotta keep your staff." Rural areas in Saskatchewan may present a unique challenge for organizations to recruit and maintain a knowledgeable, caring DSW staff in a sector that is already known for having high staff turnover.

The final staffing issue that presented a challenge for both DSWs and those they support was inconsistency in the approach of DSWs to the support of adults with ID. Sarah, Amber, and Tiffany all expressed that while everyone has a unique relationship and style when they work

with people, an inconsistent approach when it comes to addressing issues of mental health and a focus on creating an overly structured environment is detrimental to those they are there to support. According to Tiffany this was the greatest challenge facing the individuals she worked with:

We have, I think it's at this point, 11 women working at my place of employment. And they seem to be in two camps, the one that I'm in is really trying to be person centered and the other one just don't want to change the way they have been doing it. They have been doing it for so many years and I don't believe any of us that work there have formal training, it's all been on the job training. And my take is they just want their shift to go smoothly and so they don't want to change. They don't want to see things from the participants' side and they can be quite, what I call controlling. So, to me I see that the participants, they have a more difficult time when those certain people are working.

Amber echoed this concern and further detailed the negative effect this discrepancy has on those living in the home:

What I find is they know who's working, and they know what's allowed and what's not allowed between each shift. When they are with the more disciplined staff, the more structured staff they shut down. They just go about their shift or their time with that staff member. And they usually just hide in their room. They're more likely going to have an incident on those shifts.

In addition, Sarah who worked in a different group home in a rural area expressed a need for staff to be consistent when approaching issues of mental health:

...we have one staff in the home so everyone has a different approach but it's hard for the individual when you have a different staff that's telling you to do this and telling you to do that. So, we all need to be on the same page, using the same tools.

In contrast to these experiences, Julie who worked in a vocational setting did not see the value in staff always being consistent in their approach to those they support. Julie stated, "Because sometimes life doesn't happen the way you want it to...sometimes things happen. Sometimes things change. And that is a skill they need to have too...So I'm not big on consistent approaches in the work environment." She went on further to explain, "you can have

all the consistency you want but it depends on what kind of mood they're in day to day too." It is important to note that Julie emphasized that consistency was not always helpful when it came to the behavioural expressions of the individuals she worked with. She did not explicitly state how or if she felt they could help when it came to the mental health or issue underlying that behavioural expression.

## **Thematic Category 2: Strategies**

Strategies are the approaches, skills, and expertise the DSWs view as being effective means to not only support adults with ID but also to assist them during times of mental health crisis. These strategies were deemed by the participants of this study as being integral to their own success. They also felt that the use of these strategies allowed for a better life for those they supported.

**Theme 1: Developing and Maintaining Positive Relationships.** The first and most important strategy identified was the relationship that they build with everyone that they support. All five of the DSWs interviewed detailed how the development of this relationship and the trust, feelings of safety, and respect that is fostered is essential to successfully assisting those they support. This is especially true when these individuals are experiencing issues of mental health. As Tiffany stated, "it definitely makes all the difference in the world having a real relationship with them."

Julie also emphasized the importance of the relationship:

If you just walk in out of the blue and you don't know them or you haven't taken any time to get to know them and build a relationship, they're not gonna tell. They're not gonna share because they are just like you or me. They wanna feel safe and empowered, and they won't if they don't know who you are.

Sarah shared a very interesting way to think of this relationship that was shared with her by one of her supervisors:

...when you are having a shift, and you are getting along great and you are building that relationship, you are putting money in the bank so later on when you have to be more of a

boss, you have to be like we need to do this and there's no time, you gotta be a little more authoritative, then you can draw that money out of the bank.

This quote also seems to emphasize the importance of time when it comes to the development of this relationship. It takes time to make a person feel safe and respected enough to trust you during their most vulnerable moments.

Both Amber and Brandi highlighted the reasons adults with IDs struggle to develop trust in those who support them and why it takes time for that relationship to develop. As Amber put it:

...most of these people don't trust staff. They've been in group homes all their lives or institutionalized most of their lives, and staff come and go so it's building that relationship with them. To get them to trust you. To trust me so I can throw them into any situation and I don't have to worry about them.

Brandi described the situation as such:

...often times people with FASD have been slipped through the cracks their entire lives. People don't understand them. Don't support them. They have a very hard time maintaining relationships because maybe of their own behaviours and their own feelings. Initially it could be the way that they're acting. Whatever it is, they're having a hard time making connections...They're not used to someone staying in contact with them and not giving up on them. Because they've so often had people give up on them. Or they've just given up on themselves.

There are several possible reasons why individuals with ID may struggle with relationships including, low self-esteem resulting in the mistaken belief that they are not worthy of the attention or support, inconsistent or unhealthy familial relationships, and high staff turnover which results in a constant stream of individuals entering and leaving their lives.

When asked how they go about forming these relationships and gaining the trust of those they support, all the participants emphasised showing respect, being non-judgmental, and fostering a safe environment. Brandi put it simply, "I think the most important thing is letting

them know that we are not judging in any way.” Amber’s answer was even more simple, “They’re people respect them.”

Sarah’s description of how she fosters these relationships expanded on these ideas further to include the other strategies deemed successful when supporting adults with ID:

You can’t treat them like they’re all the same. So, respecting their independence too and treating them as normal as possible. They’re humans just like us and they know when you are treating them like they have an intellectual disability. So just trying to give them as much independence as possible and allowing them to make their own choices.

**Theme 2: Meet them where they’re at.** Meeting the individual where they’re at includes communicating in a manner that the individual can understand, knowing that you are hearing them, offering supports that the person wants, and developing an understanding of their perspective. According to Sarah, “each individual is different so you have to meet them where they’re at and be able to communicate in a way they can understand. You can’t expect them to meet us where we are. That’s why we are supporting them because they have disabilities.” Tiffany and Julie also emphasised this idea of meeting the individual where they are at when it comes to communication. Tiffany stressed the idea when she stated, “I listen more carefully to what it is they are trying to communicate, especially if there always seems to be more that they are trying to communicate than the surface stuff.” Julie stressed the importance of flexibility and patience during this this type of communication:

cause you are gonna ask them a question and if you use too many words they’re just gonna shut down. So, you have to wait for an answer...just slowing down enough...repeating yourself...saying it in a different way...say it louder...Sometimes you just need to shut up for a minute! So, they can hear...so they can process it. And figure out what they wanna say.

Another facet of meeting the individual where they are at involves getting to know what they have experienced and how this may have influenced their perspectives. This enables the DSW to demonstrate genuine empathy. Amber disclosed how she does this, “I listen, I question, I know their history, I’ve talked to their family members, I’ve read all their reports from twenty years ago, I have researched. This is the stuff they went through.” After the development of the

relationship Brandi emphasized how her organization was one-hundred percent voluntary and goal based which means, “I always wanna know how can I meet that persons needs and their goals.” Brandi went on to stress how important knowing about both the experiences and perspectives of those you support are in detail:

I think that it is really really really important to put yourself in their shoes. And to be realistic and to get yourself aware of what it means for individuals who are struggling on a daily basis. And don't come across as woe is them, I feel bad for them, I feel sorry kind of way. Because your pity usually doesn't get people anywhere. What they need is support. And they need understanding. And commitment...If someone is living with a cognitive disability, mental illness, physical disability, whatever it is you need to be patient and you need to be understanding. And you need to be willing to support that person in the way they need to be supported.

According to the participants, meeting the individual where they are at is multi-faceted but at its core is that it is person-centred and the adult with ID remains the centre of the supports they receive.

**Theme 3: Empowerment.** Many of the participants of this study mentioned empowerment in conjunction with the other two strategies discussed. Essentially empowerment means both encouraging and allowing the individual you are supporting to make their own choices, act upon their own independence, and dictate the supports they receive. For some DSWs it is also pushing the individual just a little or “shaking things up” so that the person does not just get stuck in a routine and expands their horizons, even just a little. As Amber put it:

Let's ruffle a few feathers. Let's see if we can change something...Like when it's quiet time where there's no incidents, the meds are all in order and she's finally starting to settle down. Let's try and push her a bit to see what she is capable of doing. What she wants to do. Testing it. And it may fail. More likely it will fail the first few times...But allowing her to grow.

Sarah stressed “trying to give them as much independence as possible and allowing them to make their own choices.” She went on to state that the approach she prefers involves “figuring out how to motivate that person to wanna be a better person. Or wanna be the person that they

could be.” Tiffany emphasized the importance of empowerment when she mentioned a question that she had been contemplating as of late, “how devastating would it be if you never got to make your own choices?” She felt that this question has altered how she approaches her work and empowerment:

They really have very very limited choices. So, it’s not much of a life. Even though they want to make it sound like it’s more like a home, it’s still institutional living...I guess I am starting to see it more from their vantage point. Instead of going to my shift and [thinking] how can I make this shift go smoothly for me, it’s looking at their lives and really trying to see how I can really support them. And help them to have the best outcome.

Amber took a very straightforward approach to empowerment, “...another thing I always do is I don’t call myself staff around them. Yeah, I’ve always called them the boss. Like, okay what do you want to do boss? Yes boss.” Amber agreed that by calling them boss she felt she was empowering them and giving them some power over their relationship.

Since Brandi worked for an organization wherein the focus was on goal-oriented, person-centred advocacy and education, she viewed empowerment as being an essential strategy to all aspects of her work. As she put it:

We are an organization that will provide lifelong supports but just based on the nature of who our clients are they might not continue to access us lifelong. So, we wanna build lifelong skills within them. Because giving people the education of how to support themselves is an incredibly powerful tool.

The participants of this study viewed empowerment as a means to allow adults with ID the opportunity to dictate how they will live their lives.

### **Thematic Category 3: Developing Competence**

Developing competencies are training experiences that the participants identified as having and/or wanting to have experienced in order to feel competent and confident as they support adults with ID with issues of mental health. They expressed that training should be



ongoing, applicable to the individuals and situations they are likely to encounter, and enhance their ability to form the safe and supportive relationships they view as essential to success.

**Theme 1: Holistic Client Knowledge.** Holistic client knowledge revolves around the DSWs' expressed desires to know the backgrounds and experiences of those they work with in conjunction with the specifics of a disability and/or disorder with which that person is diagnosed. The participants of this study appeared to feel that knowing the whole person aided in their ability to form a relationship, provided them with an idea of what to expect, and allowed them a base from which to get to know what supports the client may want or need. The first aspect of this knowledge is knowing the clients background which ties into the effective strategy of meeting the individual where they are at. As previously mentioned Amber highlighted the importance of reading files, getting to know family members, and researching client experiences in order to understand their perspective. Amber detailed how she attempted to bring this type of knowledge to her fellow staff members, "what I have done at one team meeting was I brought out a photo album...and I said here is what her past was like...just trying to bring the feelings of what these people went through."

Julie also expressed this desire to know the background of those she supports and highlighted how it helps her get to know them:

...the other thing I would really love is, I would love it if I could read their files and they were complete. Like why was so and so in Valley View for twenty years?...What is their circumstances? What is their diagnosis? Cause it can tell so much...Cause if its someone non-verbal you can't ask those things.

Julie was very careful to stress that reading files in that much detail should be reserved for individuals who are restricted in their ability to communicate their past. The other participants however, felt that this insight can be helpful even for verbal clients who may not be able to communicate how some experiences may have impacted their current behaviour or perspective.

The second aspect of holistic client knowledge stressed by the DSWs interviewed is knowing the specifics of the disabilities and disorders the individual is diagnosed with. Julie touched on this in the above quote, but Brandi really stressed how this knowledge can change a person's approach to the relationship and support:

It's really interesting to see how the dynamic can switch from the supports that they provide to the client once they learn what FASD is. Because when you're working with someone you've got your expectations about how that person should be receiving your supports and receiving your help. And if their brain isn't working properly...if their mind cannot concentrate and their body can't focus then it doesn't matter what it is that you're saying. So, it can be quite a light bulb moment for people when they realize like everything that encompasses FASD. And then it can totally switch the relationship that you have with them.

Amber provided the following example of how understanding a disability can help DSWs to better understand the behaviours of those they support which in turn makes you more cognizant of how you react to those behaviours or offer support:

You know Prader-Willi...they don't understand...At my group home I got a book and said research. This is what she is going through. She's not being as they call her manipulating. Well yeah, but that's her disability. She's always hungry. Imagine if you were always hungry. Our relationships would break too. You know what they do, how she feels. If you leave an apple on the counter, don't discipline, it's our fault for leaving it there. Of course, she's gonna take it, she's hungry. That's her disability. Searching for food.

By understanding what Prader-Willi involved, Amber felt that her colleagues would be better able to understand their client and support her in a more effective manner.

**Theme 2: Mentorship.** Several of the participants felt that organizations should offer hands on training wherein employees are shown effective strategies by another successful employee. Amber stressed how important it was for employees to be shown how to communicate effectively, foster relationships, and empower those they support because often, “the only training you get is policy and procedure”. She went on to state that mentorship is critical because:

...you can take some of these ladies to all these courses and they won't get it still...I've always been like you gotta show them. Try to bring their feelings out. Cause you can take all the courses in the world but if you don't have that heart it's not gonna work still.

When asked, what would be ideal training for DSWs to be successful and competent, Julie replied “probably following someone around one-to-one. Right now, it’s just sort of a tour, and then sit and read books for a day. I think hands on is more valuable.” Sarah alluded to the importance of both formal training and experience: “That degree in psychology has definitely helped. But some experience though is everything too. Cause you can have all the knowledge but then once you get out there and get experience you know not everything is by the book”. Gaining personal experience takes time, and the participants, indicated that it is important to learn from the experience of others through hands on mentorship.

**Theme 3: Ongoing Professional Development.** All of the participants felt that it is important for all staff to receive ongoing training in disabilities, mental health and support theories, and effective person-centered strategies. They stressed how this continued education was important in order to gain new perspectives and not get stuck in a support rut or routine. Brandi emphasized that due to the diversity of the populations that DSWs work with “...it’s really important that we make sure that our education and expertise is as broad as it can be.”

Amber and Tiffany mentioned how they worked outside of their organization to better themselves and develop professional competency. As Amber put it, “I go to conferences. I take the conference courses they offer. I do it all. I do Open Future Learning. I constantly am trying to better myself. To understand.” Tiffany really stressed how the online course Open Future Learning has changed the way she supported those she works with. When asked if she felt this new learning had improved her ability to do her job she replied, “one-hundred percent yes.”

All five of the participants listed areas that they wished they could learn more about. Julie mentioned, “suicide prevention training...more stuff on FASD cause my degree was a few years ago, and there wasn’t much research then. Same with Autism. So much has changed.” Interestingly Sarah stated, “personally for me I didn’t study a lot when I was in school about intellectual disabilities so I would like more training on that. Just the nature of Down Syndrome, learning more about FASD, Autism.” Regardless of what they specifically wanted to learn about all the DSWs interviewed felt that ongoing professional development was essential for all who support others in order to ensure competent and ethical support.

## **Ineffective Strategies**

Finally, all the DSWs mentioned either experiencing or observing others utilize support strategies that they emphasized as being ineffective. These are strategies that they viewed as being unhelpful to the individuals they support and in some cases detrimental to their mental health. As previously mentioned, both Tiffany and Amber viewed inconsistent staff approaches as being one of the biggest challenges both they and those they support face within the group home where they work. Both had noticed the ineffectiveness of the strategies utilized by some of their colleagues. For instance, Amber pointed out that these fellow employees are "...just all about routine and structure. [They] don't communicate with them, don't tell them anything, keep everything a secret." Amber felt that this type of support resulted in increased incidents and less engagement by those who lived in the group home. In Tiffany's experience these staff appeared to be more focused on being "structured, more controlling, and want their shift to go smoothly."

In her group home Sarah also observed how certain strategies are less effective:

The energy of and the approach of the staff can definitely affect the mood and emotions of the residents. I've seen with some staff in particular, they have a lot more difficulties because they don't put that relationship first unfortunately".

To really drive home her point regarding the ineffectiveness of too much control and routine, Amber shared the following story of a gentleman who recently experienced a tragic loss in his family, and who was obviously suffering, and experiencing incontinence:

He used to go to the bathroom on his own. Now he's peeing his bed, peeing his pants, not making it to the bathroom. And a lot of staff are doing it the rough way. Like we gotta keep him in routine, we have to tell him to be a big boy, real men don't pee their pants. And they start putting rules, no coffee before breakfast...but that doesn't work. He just goes backwards. What was working was good job, good job you made it.

Amber went on to state that more effort needs to be put in to "make these group homes into a real home. As much as you can, not structure...gotta make it more of a home, not just this routine. And listen to them. Give them choices."

## Summary

Based upon my discussions with the five participants of this study, it became clear that DSWs spend a large amount of time assisting and supporting adults with ID with issues of mental health. They pointed out several challenges they face on a regular basis when helping those they work with to meet their psychological and emotional needs, including staffing issues, primary and secondary disabilities, and adequate access to services.

All five DSWs emphasized the importance of the development of a trusting, safe and respectful relationship with those they support. This may take time and effort but in the end, it is vital to ensuring their ability to support the individual in an effective manner, especially when it comes to issues of mental health. It is also important to empower the individual, communicate effectively, and allow them to dictate the supports they need and goals they wish to achieve.

The DSWs interviewed stressed the importance of ongoing professional development for all staff, stating how this keeps the importance of person-centered up-to-date support techniques fresh in staffs' minds. They also emphasized hands-on experience based training as essential in order to learn effective strategies from those who have successful support relationships with those they are going to support. Finally, holistic client knowledge regarding their specific disability, psychological disorder or needs, and effective relationship strategies were seen as required to ensure that the DSWs felt prepared, confident, and competent to handle any situation they may encounter. The DSWs interviewed also identified that strategies that focused solely on structure, routine, and control have negative and often detrimental effects on adults with ID, especially when it came to their mental health and well-being.

## **Chapter 5: Discussion**

The purpose of this chapter is to examine the current research study in relation to recent literature on the importance of DSWs to the mental health of adults with ID, the barriers they face to accessing services, and their training needs. The strengths and limitations of the study are then considered. This is followed by a discussion of the implications of this study and its findings for future research and practice.

### **Summary of Findings**

Through the interviews of five DSWs three thematic categories and nine themes were identified that detailed their experiences of supporting adults with ID with issues of mental health. Within the category of challenges, primary and secondary disabilities, staffing issues, and access to adequate services were identified as struggles for both support workers and their clientele. Communication and social issues can hinder the individuals' day-to-day experiences as well as their needs in terms of emotional and psychological health. Individuals with ID have a high rate of secondary disabilities such as psychological disorders which was recognized by the participants of this study. Access to adequate supports within the leadership, medical, and mental health systems was also recognized as problematic. Several DSWs felt the frustration of not being listened to or struggling with wait times when attempting to acquire the assistance needed for their client. Finally, staffing issues such as low staff to client ratios, inconsistent approaches, and a lack of adequately trained staff to draw from were viewed as hindering the DSW's ability to provide the help needed by their clientele. In addition, these issues mean that adults with ID are not necessarily receiving the support they require in a timely manner which can have negative effects on their mental well being.

Of all the themes and aspects of their experiences emphasized by the DSWs, the development of a safe, respectful, and trusting relationship was deemed most vital to their work. This relationship is viewed as being the stepping stone from which adequate supports can be developed, goals can be met, and challenges can be addressed. This emphasis on the relationship is reminiscent of the companionship and interdependence which are emphasised within the Gentle Teaching approach to supporting vulnerable individuals (McGee & Menolascino, 2013). Without this relationship, and the time and effort that goes into fostering it, adults with ID will not feel that they are in environment where they can express their needs or ask for the help they

require. It is from this relationship base where the DSWs can then meet the individual where they are at and empower them to be independent, make their own choices, and learn the skills they need to support their own needs as they are able.

When asked what sort of training opportunities would enable them to feel confident and competent to support their clients with issues of mental health, the DSWs interviewed emphasized the importance of ongoing professional development and hands-on experience to learn effective strategies and approaches from experienced and successful colleagues. Professional development was deemed vital to ensuring that their supports were current, person-centred, and reflective of current research and theories. Hands-on mentorship is viewed as a means to learn from experience, the experiences of others, and apply educational knowledge in a supportive manner. Within the DSWs' experiences, possessing holistic client knowledge that pertains to clients' disabilities, disorders, experiences, and perspectives is a stepping stone from which the support worker can get to genuinely know their clients. Subsequently, DSWs will be able to develop realistic expectations for these clients' needs while engaging in a complex and integrated goal setting process that may involve a host of stakeholders.

Finally, and perhaps most importantly the DSWs interviewed for this study detailed several strategies that they experienced as being ineffective and perhaps even detrimental to the mental well-being of adults with ID. Approaches and strategies that overly value control, structure, and routine are viewed as negatively impacting clients in a manner that inhibits independence, limits engagement, and discourages emotional and psychological growth. As Amber stated, when colleagues who utilize these types of strategies are on shift, the residents retreat to their rooms, they do not engage, and more incidents occur. Her experiences with these strategies emphasize the negative impact this type of approach has on adults with ID.

### **Integration of Findings with Existing Literature**

#### **New Findings Not Reported in Literature**

Staff discrepancy and inconsistency in staff approaches was highlighted by several DSWs as having a negative effect on individuals' mental health and well-being. Although everyone who works with others has a different personality, style, and method of support, it is the experience of those interviewed that inconsistencies in how staff approach emotional,

psychological, and behavioural incidents can result in increased levels of distress in combination with decreased levels of engagement. Although Julie expressed disagreement with the theory of consistent approaches when it came to the behaviours of adults, the other participants all agreed that when it came to issues of mental health and psychological disorders it was important that all staff utilize the same tools and strategies in a consistent manner as a means to offer the individual a safe stable environment. Julie may view consistency as demonstrating a rigidity in situations that may require flexibility in order to respond to the immediate factors that are influencing the current behaviours. While flexibility is required within that immediate moment, consistency in approaching the underlying mental health issue may in fact prevent the outward presentation of behaviour.

The identification of both effective and ineffective support strategies provides new insights into the types of supports adults with ID in Saskatchewan are receiving. Although the concepts of person-centered planning (Robertson et al., 2007), gentle teaching (McGee & Menolascino 2013), and other overarching support guidelines have been identified in theory, the specific strategies that DSWs utilize and have experienced as successful are largely unknown. By identifying which strategies DSWs use, and deem viable and successful training education can become more focused. Although it is impossible to predict what exactly will happen when interacting with others, offering DSWs communication and relationship building skills can contribute to their success, and will at least provide them with feelings of confidence and competence from which to develop their own style of interacting effectively with their clients or residents.

Perhaps even more important was the identification of strategies that appear to be both ineffective and detrimental to the mental health of adults with ID. Although structure and routine can be very important to some people and may even alleviate anxiety, it appears that an over emphasis can result in a highly controlling environment that results in disengagement, increased tension, and a greater numbers of negative incidents.

### **Findings in Literature but Not in Present Study**

Although not contained within the formal literature review, an online search of major CBOs in Saskatchewan indicated that they upheld hiring requirements wherein eligible employees must have a post-secondary education in the form of a relevant degree or applicable



certificate in order to be considered for a position. Based on the information gathered from the DSWs who participated in the current study this requirement may not be true for smaller organizations located within small, rural areas of the province. Both Amber and Tiffany stated that requiring such education would mean never having adequate numbers of staff in their group home. Group homes in small towns continue to rely on the labour force that is readily available which unfortunately may mean their staff are less likely to have formal education and training in psychology, disability supports, theories regarding person-centred planning, and crisis intervention. This finding highlights the importance of within organization training and ongoing professional development so that the workforce that is available to small town organizations can offer their clients the best supports available, and appropriately assist with mental health and well-being.

### **Findings Confirmed in the Literature**

Several of the results of this study align with the current research literature. The finding that DSWs are in fact regularly supporting adults with ID with issues of mental health is the first example. Lunsky et al. (2007) found that individuals with both intellectual disabilities and issues of mental health were more likely to seek assistance from intellectual disability service providers or family physicians when faced with behavioural or mental issues. Lippold and Burns (2011) found that paid carers tend to provide adults with ID with the vast majority of social and emotional support. This was reflective of the experiences described by the DSWs in this study.

In addition, the key informants surveyed by Lunsky et al (2007), which included paid carers, reported that generic mental health services were ill-equipped to meet the needs of this population. Many of the DSWs interviewed expressed concern regarding waitlists, medications issues, and communication barriers with psychiatrists as challenging for both themselves and their clients. Weiss et al (2009) found that caregivers who participated in their research detailed several of the same challenges when utilizing emergency departments in Ontario in times of severe psychiatric crisis. Furthermore, research by Lennox et al (1997) as well as Weiss et al (2010) pointed out the lack of specialised training of general practitioners and psychologists when it comes to working with individuals with dual disabilities. This lack of specialised training is reflected in the reported struggles of the DSWs as they attempt to help adults with ID access adequate services.

Finally, Rose et al (2007) found that employees of intellectual disability agencies do not necessarily receive any formal training in the areas surrounding mental health issues. The participants of this study all expressed that they also did not receive any specialized training from their organizations in these areas.

One of the main findings of the current study was that DSWs felt that ongoing professional development is essential to offering confident and competent supports. Mohr et al (2002) and Costello et al (2006) found that by offering staff training and workshops on mental health and dual diagnosis, service agencies enable their staff to more competently offer the mental health assistance needed by adults with ID.

### **Strengths of the Current Study**

The principle strength of this study is that it investigated a phenomenon which was previously not found in the research literature—the experiences of direct support workers as they support adults with intellectual disabilities with issues of mental health. Previous research has highlighted DSWs importance to the emotional, functional, and psychological health of those they support (Lunsky et al, 2007; Lippold & Burns, 2011). Mohr et al (2002) and Costello et al (2006) also indicated the importance of specialized training to increase the competence of DSWs in this area. But none attempted to gather the specific experiences and opinions of DSWs on this matter. This study attempted to gain their perspective and was able to obtain a sample of recruited participants with some diversity regarding education, organization, type of supports provided, and location within the province of Saskatchewan.

My previous role as a direct support worker as well as training in counselling assisted in the development of a rapport with the participants. In addition, my knowledge regarding respecting and maintaining the privacy and confidentiality of adults with ID served by their organizations eased their discomfort and reassured them that I would do nothing to jeopardize the rights of those individuals. I have experience working in a vocational setting as well as a group home offering a wide variety of supports which allowed me, as a researcher, to approach the research from a common background and similar experiences which facilitated data collection and analysis.

### **Limitations of Current Study**

There are a number of limitations of the current research study. First, although the volunteer participants were quite diverse they all appeared to be quite like minded in terms of their person-centered approach to supporting adults with ID. This information indicates that they all share a particular perspective when it comes to the supports and strategies they utilize. This perspective may differ from the larger population of individuals who work in this sector. In addition, the participants of this study may have been compelled to participate due to frustration they felt with situations within their current organization. This frustration may also have coloured their perspectives and suggestions which would be reflected in the data.

In addition, this study exclusively considered the perspectives and experiences of DSWs as to the challenges, strategies, and competency development pathways to assisting adults with ID with issues of mental health. There are several other perspectives such as, the individual, organizational leadership, family members, and medical or mental health professionals that would offer additional insight or alternative perspectives in this area. Although the findings presented within this study are a valid representation of the experience, the findings represent a partial and narrow representation of the experience.

### **Implications for Future Research**

The current research study is distinct in its focus on the experiences of DSWs as they support adults with ID with issues of mental health and well-being. This focus attempts to fill a gap in the research to gain the perspective of paid carers who play such an important role in the lives of these individuals often without specialised training to necessarily do so. It also attempted to determine the types of training DSWs feel will help them to more confidently and competently offer this much-needed assistance. However, further research is needed.

This study was limited in the number of participants. Therefore, the first recommendation is to conduct a study with a larger sample size. This study could expand to include further perspectives and experiences. For example, the perspectives of the individuals themselves, family members, and other professionals would add valuable insight. They may be able to offer valuable information regarding effective skills and strategies that DSWs may find fruitful. Also, a large-scale study of DSWs in the province may investigate what current

professional development opportunities are available to them, who accesses these opportunities, and more importantly, what topics DSWs would suggest as being beneficial for future professional development experiences. This research may provide a baseline from which recommendations for future professional opportunities may be made.

It is also recommended that future research be conducted within the rural context in order to develop a better understanding of the unique situation these organizations face. Access to adequate staff and mental health services may prove to be even more challenging in these areas. Future research could then compare the urban and rural experiences which may affect the type and/or scope of the training programs or professional development required by these organizations.

Another area of future research may be to investigate the stigma surrounding mental health as it is perceived by adults with ID. This stigma may prevent these individuals from sharing their struggles with mental health with DSWs, doctors, family members, and mental health professionals. An extension of this investigation would be to determine ways in which this stigma could be reduced in order to help clients to feel more comfortable with sharing their concerns, experiences, and issues of mental health with individuals outside of their close support relationships. An individual's perceptions regarding mental health and the related stigma may restrict their willingness to seek assistance. By exploring these areas another supportive direction for adults with ID may be identified.

Community based organizations experience a high degree of staff turnover. Although research has been conducted within Saskatchewan into staff recruitment, orientation and training as a means to address this situation (Li, 2004), it is recommended that future research investigate the specific effects this turnover has on relationship building between DSWs and those they support. The current study highlighted how important this relationship is to assisting individuals with ID with issues affecting mental health. Further targeted research is needed to determine if there is a link between high staff turnover and continued relationship difficulties for this already vulnerable population, as well as the effect they have on the individuals' willingness to discuss mental health issues. Then specific staff supports may be investigated in order determine training, and professional development to aid in relationship building while at the same time addressing the high rate of staff turnover.

During the course of the current study Amber related a poignant story of the treatment of a poor gentleman who in the throes of grief was experiencing physical and behavioural difficulties. The man had recently experienced the death of a family member and in his bereavement, was having challenges with incontinence. Rather than offering positive support several of Amber's co-workers were berating him and appeared to be more focused on putting a stop to a problem behaviour rather than assisting him with his mental health needs. This story highlights the need for further research into perceived negative treatment as observed by DSWs, how to monitor for such treatment, and training initiatives that can be implemented to ensure that such instances of negative supports do not continue to happen. By investigating the possible negative that unfortunately continues to occur in these situations, support services can be improved to better meet the needs of individuals with ID.

Finally, further research is recommended into the unique support situations of vocational versus group home organizations. Future studies may indicate that more specific skills or training may be required in each setting. As Julie pointed out routine and consistency cannot be guaranteed in a work environment. Both DSWs and adults with ID may need to develop different skills in order to adapt to different environments.

### **Implications for CBOs and DSWs**

#### **Community Based Organizations**

The largest implication for CBOs is that they need to realize and acknowledge the importance of DSWs to the mental health and well-being of the clients they serve. The current study indicates that DSWs assist adults with ID daily, face numerous challenges in doing so, and seek information and training in order to confidently and competently offer the supports required by their clients. Although it may not be the stated mandate of their organization, CBOs must recognize the needs of their clients and ensure that their staff have the capacity to meet those needs.

Another implication of the current study is that there may be a need to develop and implement guidelines and professional practice standards for DSWs not just within Saskatchewan but throughout the country. These guidelines would ensure consistent hiring practices, training requirements, and professional development initiatives. Through the

implementation of these standards CBOs can offer the best support possible to a highly vulnerable facet of our society.

The findings of the current study also suggest that DSWs feel that ongoing professional development would aid them to stay current on appropriate positive support strategies and research based interventions. Some participants also pointed out the reluctance of some staff to seek professional development voluntarily. CBOs may want to consider offering their staff more professional development and requiring that staff participate in order to ensure that they are approaching situations in a manner that is both positive and consistent.

### **Direct Support Workers**

The findings of this study have implications for DSWs who support adults with ID who struggle with issues of mental health. Of greatest importance, the findings highlighted several strategies that the DSWs have experienced as being effective in the successful support of individuals facing emotional or psychological crises. Other DSWs may find these insights useful and incorporate them into their own support relationships. Finally, they may be inspired by the suggestions made regarding developing competency and advocate for the implementation of new training and professional development initiatives within their own organizations.

### **Researcher Self-Reflection**

Due to my own personal experiences and perspectives there were several occasions throughout the research study where I struggled to listen to the perspectives and experiences of the DSWs interviewed. In particular, I disagreed with Julie's opinions regarding consistency of approach by staff. It took me a great deal of restraint to allow her to express her perspective and experience on the matter. Eventually though because I managed to not inject my own thoughts, I could see her side and understand that she was more focused on dealing with behaviours rather than addressing the possible mental struggle behind that behaviour. Many DSWs may continue to focus on the outward expression of mental health struggles by those they support without considering the root of the problem. I think training in mental health issues and dual diagnosis would be a helpful remedy to this focus. By providing professional development and hands-on mentorship in the specifics of the symptoms of psychiatric disorders, medication side effects, and skills specific to communication and relationship building, organizations can better equip their

employees to assist adults with ID who are struggling with poor mental health. In addition, it will enable them to recognize vulnerabilities and provide them the confidence to advocate on behalf of those they work with in order to prevent the worsening of a mental health issue, and to promote positive mental health. As I have received more professional training in these areas I have noticed a shift in how I approach my relationships, a deeper understanding of the needs of those I support, and a confidence in my skill set. I think all DSWs could benefit from advanced training.

In addition, I also struggled on a couple of occasions to not lead the person being interviewed to the conclusion that I assumed they were making based upon my own experiences. This was a struggle that I anticipated going into the project however, so I made sure to be cognizant of it throughout each interview. I had not, however, considered how my experience would affect the answers given by the participants. A number of different times the DSW would say “well you know what I’m trying to say” and I would have to push them for clarifications in order to ensure that the data accurately reflected their experiences and not mine.

The perspectives of the participants of this study really did not surprise me. In fact, I found it quite reassuring to know that others shared my experiences, struggles, and perspectives regarding the support of adults with ID. I really related to the experiences of Amber and Tiffany regarding the negative effects of staff inconsistency and overly structured, controlling support strategies. I have witnessed how these types of challenges can hinder the engagement and mental health of adults with ID. I felt a sense of hope and pride in the efforts of these two fellow DSWs as they fought to bring about change within their organization. In addition, the perspectives put forth by the participants aligned with my more current training in psychology, disability, and education.

The experience of speaking to DSWs about their experiences gave me hope that although organizations in Saskatchewan have a long way to go in assisting adults with ID with their mental health and well-being, they are moving in the right direction. The DSWs interviewed are a testament to the progress being made in ensuring that adults with ID are offered positive supportive environments where they feel safe and empowered enough to make independent choices, express themselves, and advocate for the supports that will benefit them.

## **Conclusion**

The three research questions in this study looked at the challenges faced by adults with ID and the DSWs who support them. In particular, this study explored client struggles with mental health challenges, the strategies DSWs use to offer assistance, and how prepared DSWs are to offer these supports. The experiences and opinions of the DSWs were classified into the three thematic categories of Challenges, Strategies, and Developing Competency. Three themes within each of the thematic categories were then identified. Within the category of challenges, the themes of primary and secondary disabilities, staffing issues, and access to adequate services were identified as posing challenges to both DSWs and those they support. The category of strategies resulted in the themes of relationship, empowerment, and meeting them where they are at. Finally, developing competency included the themes of holistic client knowledge, mentorship, and professional development. The findings of this study indicate that DSWs in Saskatchewan are regularly assisting adults with ID with issues of mental health regardless of a lack of training to do so. Despite this the participants of this study have cultivated strategies that they feel allow them to successfully help those they support with their mental health challenges. They also identified areas of training that they feel will help DSWs to feel confident and competent in their ability to offer the supports their clients need. The significance of the current study lies in the fact that through understanding of experience we can ensure better practice and protection of the vulnerable in society.



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## Appendix A: Informed Consent Form



## *Participant Consent Form*

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**Project Title:** Mental Health and Intellectual Disability: The Experiences of Disability Support Workers in Relation to the Mental Health Needs of Clients

**Researcher(s):** Tara Thiemann, Graduate Student, School and Counselling Psychology, University of Saskatchewan, [tat841@mail.usask.ca](mailto:tat841@mail.usask.ca)

**Supervisor:** Dr. Tim Claypool

**Purpose(s) and Objective(s) of the Research:**

- Exploring and understanding the perspectives and experiences of direct support workers as they assist adults with intellectual disabilities through issues of mental health and well-being.
- Gain insight into DSW's training competencies and needs.

**Procedures:**

- Individual interview to discuss experiences and perceptions of supporting ID individuals with issues of mental health in great depth. Session will last approximately 1 hour and be audio recorded
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Potential Risks:**

- There are no known or anticipated risks to you by participating in this research

**Potential Benefits:**

- You will have the benefit of contributing to the understanding of the mental health and well-being of adults with intellectual disabilities.
- You will have the positive opportunity to talk with the researcher about a topic that is important to you as well as share common experiences and challenges
- A small gift will be provided in recognition of your time

**Confidentiality:**

- All information obtained from the interview session will be kept confidential.
- Your participation will be kept confidential from your employing community based organization.
- **Storage of Data:**
  - Consent forms, questionnaires, and recordings from the focus group sessions will be stored separately in locked cabinets within the care of the primary researcher.
  - After a period of 7 years, when the data no longer required, the data will be destroyed.

**Right to Withdraw:**

- Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.



- Should you wish to withdraw, you have the right to do so (see below) and the data/information you have provided will be destroyed.
- Your right to withdraw data from the study will apply until results have been pooled. After this date, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

**Follow up:**

- To obtain results from the study, please contact the University of Saskatchewan

**Questions or Concerns:**

- Contact the researcher(s) using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
<i>Researcher's Signature</i>	<i>Date</i>	

*I consent to being audio-recorded during the course of the interview session.*

<i>Name of Participant</i>	<i>Signature</i>
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***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

## Appendix B: Telephone Participant Consent Form



## *Telephone Participant Consent Form*

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**Project Title:** Mental Health and Intellectual Disabilities: The Experiences of Disability Support Workers in Relation to the Mental Health Needs of Clients

**Researcher(s):** Tara Thiemann, Graduate Student, School and Counselling Psychology, University of Saskatchewan, [tat841@mail.usask.ca](mailto:tat841@mail.usask.ca)

**Supervisor:** Tim Claypool, Educational Psychology and Special Education, University of Saskatchewan, [tim.claypool@usask.ca](mailto:tim.claypool@usask.ca)

### **Purpose(s) and Objective(s) of the Research:**

- Exploring and understanding the perspectives and experiences of direct support workers (DSW) as they assist adults with intellectual disabilities (ID) through issues of mental health and well-being.
- Gain insight into DSW's training competencies and needs.

### **Procedures:**

- Individual interview at a private location of convenience to discuss experiences and perceptions of supporting ID individuals with issues of mental health in great depth.
- Interview session will last approximately 1 hour.
- The interview will be audio recorded; audio recorder may be turned off at any time upon participant request.
- All participants will be asked to read, review, provide feedback, and approve the transcript of their personal interview. This can be done through email or in-person as requested by the participant. Once the participant approves of the transcript of their interview, they will be asked to sign a transcript release form.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

### **Potential Risks:**

- There are no known or anticipated risks to you by participating in this research

### **Potential Benefits:**

- You will have the benefit of contributing to the understanding of the mental health and well-being of adults with intellectual disabilities.
- You will have the positive opportunity to talk with the researcher about a topic that is important to you as well as share common experiences and challenges
- A small gift (\$10 Tim Hortons gift card) will be provided in recognition of your time

### **Confidentiality:**

- All information obtained from the interview session will be kept confidential.
- Your participation will be kept confidential from your employing community based organization.
- **Storage of Data:**
  - Consent forms, questionnaires, and recordings from the interview sessions will be stored separately in locked cabinets within the care of the primary researcher.

- After a period of 7 years, when the data no longer required, the data will be destroyed.

**Right to Withdraw:**

- Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Should you wish to withdraw, you have the right to do so (see below) and the data/information you have provided will be destroyed.
- Your right to withdraw data from the study will apply until results have been pooled. After this date, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

**Follow up:**

- To obtain results from the study, please contact Tara Thiemann, Graduate Student, School and Counselling Psychology, University of Saskatchewan, [tat841@mail.usask.ca](mailto:tat841@mail.usask.ca)

**Questions or Concerns:**

- Contact the researcher(s) using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

I read and explained this Consent Form to the participant before receiving the participant's consent, and the participant had knowledge of its contents and appeared to understand it.

\_\_\_\_\_  
*Name of Participant*

\_\_\_\_\_  
*Researcher's Signature*

*The participant consented to being audio-recorded during the course of the telephone interview session.*

\_\_\_\_\_  
*Name of Participant*

\_\_\_\_\_  
*Researcher's Signature*

***Please retain a copy of this consent for your records, a copy will be kept by the researcher.***

**Appendix C: Transcript Release Form**



***Data/Transcript Release Form***

---

Title: Mental Health and Intellectual Disabilities: The Experiences of Disability Support Workers in Relation to the Mental Health Needs of Clients

I, \_\_\_\_\_, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Tara Thiemann. I hereby authorize the release of this transcript to Tara Thiemann to be used in the manner described in the Consent Form. I have received a copy of this Data/Transcript Release Form for my own records.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of researcher

## Appendix D: Call to Participate

### Department of School and Counselling *Psychology* University of Saskatchewan



#### PARTICIPANTS NEEDED FOR RESEARCH IN *THE MENTAL HEALTH OF ADULTS WITH INTELLECTUAL DISABILITIES*

**We are looking for volunteers to take part in a study of  
*Direct Support Workers who support adults with intellectual disabilities  
and mental health concerns.***

As a participant in this study, you would be asked to:

- *Participate in a one hour interview to discuss those experiences and your perceptions of them*

#### Participation Criteria:

- 3 + months employment working with Adults with ID
- 3 + months working with a fairly consistent set of service users
- At least one experience providing support to an adult with ID experiencing issues affecting mental health.

For more information about this study, or to volunteer for this study,  
please contact:

*Tara Thiemann*

*School & Counselling Psychology*

Email: *tat841@mail.usask.ca*

**This study has been reviewed by, and received approval  
through, the Research Ethics Office, University of Saskatchewan.**



**usask.ca**

## Appendix E: Semi-Structured Interview Guide

- 1) Please talk about your experiences working with adults with ID and mental health difficulties.
  - a) Difficulties?
  - b) Successes?
- 2) What are some of the personal and social challenges with which you have assisted adults with ID as you support their daily activities?
- 3) Have you ever had the experience of a situation where you had to identify the specific mental health needs or symptoms of someone you supported?
  - a) What was that like?
  - b) Are there challenges? Things that make it difficult?
  - c) Are there facilitators? Things that make it easier?
- 4) What kinds of assistance would you say you have provided to adults with ID experiencing mental health challenges? How do you provide the support they need?
- 5) How often do you need to provide this type of support?
  - a) What percentage of your average workday is spent focusing on client mental health?
- 6) How prepared are you to offer these types of supports?
- 7) Does the need to provide these types of supports interrupt/interfere with your ability to carry out the specific job requirements of your position?
  - a) How often would you say this occurs?
  - b) What do you feel are the consequences of this?
- 8) What kind of training have you received to work with adults with ID experiencing issues of mental health?

- a) Strengths?
  - b) Weaknesses?
  - c) Suggestions of training that would make you feel more confident when working with adults with ID experiencing issues of mental health and well-being?
- 9) How could service provision for adults with ID experiencing mental health issues be improved?