EXPLORING PERCEPTIONS OF POSITIVE MENTAL HEALTH IN YOUNG ADULTS
WITH INTELLECTUAL DISABILITIES

by

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Abstract

Individuals with intellectual disabilities are at a greater risk of developing mental health difficulties than typically developing individuals (Munir, 2016). One way that mental health difficulties have been targeted and treated in recent years is by providing people with education about mental health, what it is and strategies to promote it. Mental health literacy is the process by which people learn how to obtain and maintain positive mental health; understanding mental disorders and their treatments; decreasing stigma related to mental disorders; and enhancing help-seeking efficacy (Kutcher, Wei, & Coniglio, 2016). When individuals understand what positive mental health is, they are more likely to take steps that contribute to it (Barry & Jenkins, 2007). While individuals with intellectual disabilities experience higher than average levels of mental health difficulties, especially young adults, there is limited research about how they view mental health, specifically, positive mental health. The researcher in this study sought to gain a better understanding of how young adults with intellectual disabilities conceptualize and define the concept of positive mental health, by employing a phenomenographic methodology. Eight participants were interviewed by the researcher and the qualitative interviews were analyzed in accordance to the phenomenographic method. Categories of description were identified through data analysis, which provided insight into how study participants defined positive mental health. The main categories of description that emerged from the data included defining positive mental health as related to physical health, and participants expressing that they were not sure what positive mental health was. Additionally, positive qualities were part of some individual's definition (including happiness and positive actions), and mental health issues. This study provides important information to clinicians as it highlights the need for further research about

how to best support individuals with intellectual disabilities in their psycho-education around mental health issues.

Lay Summary

Young people with intellectual disabilities are at a greater risk of developing mental health difficulties compared to others who do not have intellectual disabilities. One way that mental health difficulties have been treated in recent years is by providing people with education about mental health. This study worked to understand how young adults with intellectual disabilities understand and define the concept of positive mental health. Interactive interviews were conducted with eight participants to better understand their views of positive mental health. The researcher looked at the data and sorted it into similar categories. The main categories that were identified included defining positive mental health as related to physical health, and participants expressing that they were not sure what it was. Participants also expressed that positive qualities (happiness and positive actions) were part of the definition. Lastly, mental health illness was part of their definition of positive mental health.

Preface

The content of this thesis is based on the unpublished work conducted by Darcie-Anne Bailey, the Graduate student, under the supervision of Dr. Laurie Ford. The research conducted for this study was approved by the Behavioral Research Ethics Board (BREB) at the University of British Columbia under the certificate number H16-02638-A001.

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To all those that learn differently or experience mental health issues, may this study help you feel less alone.

Chapter 1: Introduction

Overview

Mental health concerns are commonly experienced by individuals with intellectual disabilities and are experienced at a disproportionate amount compared to typically developing populations (Chen et al., 2006; Cooper et al., 2007; Razza et al. 2014; Reid et al., 2011). In the population, 1-3% have an intellectual disability. Those that have an intellectual disability are 3 to 4 times more likely to develop mental health difficulties in their lifetime compared to the general population (Munir, 2016). There are a number of factors that contribute to the development of mental health difficulties in individuals with intellectual disability. Lower cognitive abilities are often positively related to the development of mental health disorders such as depression, schizophrenia, and anxiety (Koenen et al., 2009). People with an intellectual disability are more prone to experiencing life events that are associated with the developmental of mental health difficulties and perceptions of stigma (Dagnan & Waring, 2004; Jones, 2014; Martorell et al., 2009).

High school students and young adults with intellectual disabilities are particularly susceptible to the development of mental health difficulties, as the transition out of high school creates anxiety for this population and can exacerbate the development of mental health difficulties (Kaehne, 2011; Scior & Grierson, 2004). Considering these various limitations/barriers, people with intellectual disabilities are at a greater risk of developing mental health disorders, compared to typically developing populations. While there is increased risk of developing mental health difficulties, there is very little research exploring the unique perspectives of people with intellectual disabilities and their experiences with mental health difficulties.

One of the protective factors that exist for the development of mental health difficulties is understanding what mental health is, specifically, mental health literacy. Mental health literacy involves understanding how to obtain and maintain positive mental health; understanding mental disorders and their treatments; decreasing stigma related to mental disorders; and enhancing help-seeking efficacy (Kutcher, Wei, & Coniglio 2016). Improved mental health literacy helps to facilitate help-seeking behaviour and reduces stigma (Gulliver, Griffiths, & Christensen 2010). One component of mental health literacy is positive mental health. Understanding positive mental health can act as a protective factor from the development of mental health difficulties. Individuals who understand positive mental health are able to identify factors that contribute to it and may be more likely to seek out such factors (Barry & Jenkins, 2007).

Given that individuals with intellectual disabilities are affected by mental health difficulties at a higher prevalence rate than the general population (Razza et al. 2014), and that young adults with intellectual disabilities are particularly vulnerable due to increased anxiety during the transition outside of high school (Kaehne, 2011), understanding positive mental health is important among this population. This study is an important contribution to the literature because it provides a first look at the perceptions and understandings that young adults with intellectual disabilities have about positive mental health. By understanding their perceptions and understanding about this topic, interventions can be better designed and implemented keeping in mind the prior knowledge that this population brings regarding positive mental health.

Definition of Key Terms

Positive mental health. In the present study, this term is defined according to the Public Health Agency of Canada's definition: "the capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive

sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice, interconnections and personal dignity” (Public Health Agency of Canada; 2014, p. 3).

Mental health literacy. This term is used to describe the “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (Jorm et al., 1997, p. 182).

Intellectual disability. This term is used to describe individuals who have been identified as having “deficits in intellectual and adaptive functioning in terms of conceptual, social, and practical domains originating in the developmental period”, as assessed by a trained professional (DSM-5, 2013, p. 33). The terms developmental delay and mental retardation have also been used within previous literature and publications. Those with intellectual disabilities vary with regard to their level of functional impact. Depending on an individual’s level of impairment, different descriptors are used to describe such individuals (ranging from Mild – Profound). In the current study, participants who were interviewed were in the mild to moderate range. Had participants being interviewed had a severe to profound intellectual disability results likely would have varied.

Summary

Individuals with intellectual disability provide a unique and informative perspective about mental health difficulties, yet they are often not the key informants in studies that examine mental health in ID. They bring unique experiences and experiences that are crucial to understand in order to develop and implement interventions that target mental health difficulties in this population. Their increased risk of developing mental health difficulties, in particular, during young adulthood, make it very important to target. One of the ways to decrease the risk of developing mental health difficulties is to ensure that people with intellectual disabilities

understand mental health and understand what contributes to positive mental health. If individuals understand positive mental health and the factors that contribute to it, they may be more likely to seek out such resources. A goal of this study is to uniquely endeavor to understand the conceptions that individuals have about positive mental health.

Chapter 2: Literature Review

Overview

Mental health is an important factor that is key to individuals' ability to thrive in life. Mental illness directly impacts all Canadians at some point within their lifetime. According to the Canadian Mental Health Association, approximately 20% of Canadians experience a mental illness in their lifetime. In a report created by the Canadian Mental Health Association, they explain that mental illness has become an increasing problem, in particular with youth, and that Canada ranks third highest for youth suicide rate in the industrialized world (2016). The prevalence rate for intellectual disability in the general population are estimated between 1-3%, with the rate of developing mental health problems being 3 to 4 times higher in this specific population (Munir, 2016).

Mental Health Difficulties in Individuals with Intellectual Disabilities

People with intellectual disabilities account for about three percent of the population in the world. The prevalence rates of mental health disorders are consistently higher in people with intellectual disabilities compared to typically developing populations (Chen et al., 2006; Cooper et al., 2007; Reid et al., 2011). Emerson and Hatton (2007) conducted a study examining the prevalence rates of mental health difficulties and psychiatric disorders in children and adolescents with and without intellectual disabilities by looking at national statistics in England. Of individuals with intellectual disabilities, 36% were diagnosed with a psychiatric disorder compared to 8% who did not have intellectual disabilities .

Chen and colleagues (2006) explored the link between mild (borderline) intellectual disability among preschool children (i.e., four-years old) with emotional and behavioral problems in young adulthood, by tracking the physical, neurological, cognitive, and

socioemotional development and health of a birth cohort of 4025 children born between 1959 and 1965. Children were assessed at 4, 8, and 12 months; and at ages 3, 4, 7, and 8 years. The researchers assessed children's cognitive abilities using the Stanford-Binet Intelligence Scale (Form L-M). Children with IQ ranges between 70 and 80 were classified as having *borderline mental retardation*, and children with IQ scores below 70 were labeled *definite mental retardation*. In 1992 through 1994 participants who had completed the assessments in childhood completed adult assessments, which consisted of researchers administering a questionnaire that explored personal characteristics, health conditions, and social development outcomes. Researchers asked individuals about emotional problems, general mental health, tobacco use, and alcohol use. People who had IQs below 80 had higher rates of emotional and behavioural problems, compared to those with higher IQ scores. The relationship between IQ and emotional and behavioural problems became more pronounced for individuals with IQ's under 70. Emotional and behavioural problems were not assessed using standardized measures however, and thus these findings must be interpreted with caution. Additionally, it is noteworthy that researchers did not examine children's adaptive functioning in their assessment of IQ. Despite this limitation, the study done by Chen and colleague's illuminates the relationship between lower levels of cognitive abilities and emotional and behavioural difficulties in individuals with intellectual disabilities.

Factors Influencing Mental Health Difficulties and Intellectual Disability

Cognitive Reserve Hypothesis. The Cognitive Reserve Hypothesis provides a framework for understanding why individuals with intellectual disabilities develop mental health difficulties at a higher prevalence compared to the general population. The theory asserts that "individual differences in brain structure (e.g., density of neuronal synapses) and function (e.g.,

processing efficiency) are thought to buffer the effects of neuropathology (Koenen et al. 2009, p. 50).

Koenen and colleagues (2009) conducted a longitudinal study in order to better understand the Cognitive Reserve Hypothesis and its relation to the development of mental health difficulties for individuals with intellectual disabilities. Koenen et al. (2009) studied a birth cohort (born from 1972-1973) until age 32. Participant's IQ's were assessed using the WISC-R at ages 7, 9, and 11, and the scores were averaged across the three-year period. At ages 18, 21, 26, and 32 participants were assessed for mental disorders using the DSM-IV. It was hypothesized that people with lower levels of IQ would have increased levels of mental disorders later in life because of the *Cognitive Reserve Hypothesis*. Koenen's research further supported this hypothesis by finding an association between lower childhood IQ as assessed by the WISC-R (IQ 85 and below), and major depression and generalized anxiety. The researchers concluded that low cognitive abilities (lower childhood IQ's) was directly related to, and acted as an antecedent to, the development of a number of mental health disorders (including major depressive disorder, schizophrenia spectrum disorder, and many anxiety disorders in adulthood). The relationship between low IQ and mental disorders remained strong after confounding variables were controlled for (such as socio-economic status, low birth weight, and childhood maltreatment).

Life circumstances. The literature also suggests that people with intellectual disabilities are more prone to experiencing life circumstances that are associated with the development of mental health difficulties, such as unemployment, debt, stigmatization, lack of self-determination, health difficulties, physical and sexual abuse, and lack of meaningful friendships and intimate relationships (Jones, 2014; Martorell et al., 2009). Martorell et al. (2009)

investigated the associations of life events, traumatic experiences, and psychiatric disorders in people with intellectual disabilities. One hundred and seventy-seven adults with intellectual disabilities were interviewed using the Psychiatric Assessment for Adults with Developmental Disabilities. Additionally, their caregivers completed a checklist of life events experienced over the past 12 months and the presence of traumatic events. Traumatic events were assessed through Allen's Trauma History Screen (Allen, Huntoon, & Evans, 1999), a screener used in multiple settings to assess trauma.

According to caregiver ratings, of participants interviewed, 75% had experienced a traumatic event during their life span, and 50% had experienced a traumatic event within the last year. Results indicated that individuals who reported having experienced a traumatic event in the last 12 months had increased odds of the presence of a psychiatric disorder. However, checklists were administered to key informants rather than directly to participants due to difficulties in communicating, which could mean undisclosed events were not reported. Additionally, this study did not support a causal relationship between traumatic events in those with intellectual disabilities and the development of psychiatric conditions, but rather presented a significant positive correlational relationship.

Social interactions. Not only do individuals with intellectual disabilities experience life circumstances that can exacerbate mental health difficulties, but the social interactions they experience may also contribute to a negative view of self and mental health difficulties. Individuals with intellectual disabilities often experience social interactions that are negative, which in turn can result in the development of low self-esteem, stress, and mental health issues (Dagnan & Waring, 2004). Dagnan and Waring (2004) explored the link between social experiences of individuals with intellectual disabilities and core cognitive processes (e.g.,

perceptions of stigma, core negative evaluations and social comparison) that have in the past been related to psychological disorders. Thirty-nine people with intellectual disabilities completed self-report measures. Correlational analysis indicated a positive association between negative beliefs about self and experiencing the feeling of being different, which the authors explain can be described as an internalizing stigma. Additionally, a relationship existed between recognizing oneself as stigmatized, negative self-evaluations and social attractiveness (part of social comparison domain). Clinically, this study is important because the findings suggest that perceptions of stigma can lead to negative self-evaluations and distress for individuals with intellectual disabilities (Dagnan & Waring, 2004).

Jones (2012) explored adolescents with intellectual disabilities self-perceptions. Fifty-one qualitative interviews were conducted with individuals with intellectual disabilities, as well as parents and teachers. Participants, recruited from middle and high schools, ranged from 11 to 20 years old ($M=15.97$). Fifty-five percent of the individuals with intellectual disabilities described themselves by highlighting their disabilities. Adolescents viewed their disability through a framework of social exclusion or limited opportunities, as described by the researcher. For example, adolescents referred to riding the “special bus” or not being included in “regular classrooms.” Individuals with intellectual disabilities often begin to identify that they have differences between themselves and their typically developing peers at around the time of adolescence. The researcher pointed out that while there have been changes put in place to promote viewing intellectual disabilities from the paradigm of supports vs. deficits, those that identify with such disabilities continue to view themselves through a deficit lens. This realization may also continue throughout young adulthood, and can impact self-concept (Jones, 2012).

Additionally, the stigma that is related to mental health difficulties can further compound such negative views of self (Thornicroft, 2006). Adolescents with intellectual disabilities have more negative self-concepts compared to their typically developing peers (Popovici & Buic-Belciu, 2013; Uno & Leonardson, 1980). One common theme between individuals that have disabilities is that they often define themselves using their disabilities (Popovici & Buic-Belciu, 2013). The literature suggests that individuals with intellectual disabilities have experiences that may exacerbate the developmental of mental health difficulties. Individual's cognitive processes (cognitive reserve hypothesis), their life events, and social interactions may negatively impact individual's view of self and can lead to increases in mental health difficulties.

Young Adults and Mental Health Difficulties

Mental health illnesses are one of the leading health challenges for people in the second decade of their life, with about 70% of mental illnesses being diagnosed before the age of 25 years (Kessler et al., 2005, Whiteford et al., 2013). Given that young adults are particularly vulnerable to developing mental health difficulties, it is important for this age group to learn about mental health literacy.

While young adults, in general, are susceptible to mental health difficulties, young adults with intellectual disabilities are particularly vulnerable. The transition for young adults with intellectual disabilities from high-school education to post-secondary education is often tumultuous. A 2012 Canadian Survey on Disability indicated that 40% of students with disabilities who went on to post-secondary studies were avoided or excluded, and 27% experienced bullying. 29% of individuals with mild disabilities reported that they were not working (Arim, 2015). Scior and Grierson (2004) reported that this transition is often a time of worry for young people.

Kaehne (2011) conducted a study investigating mental health professional's experience assisting people with intellectual disabilities in their transition from childhood/adolescent to adulthood. He asked participants about gaps in service provision and what they identified as the main obstacles for a smooth transition. Eight participants were interviewed about their experiences. Participants explained that the post-education transition can increase the risk of mental health problems for those with intellectual disabilities. When participants were asked about the transition in Kaehne's (2011) study they expressed feelings of marginalization in social and educational contexts, and that helping individuals transition in these contexts is a disruptive transition for young people with intellectual disabilities that can impact future outcomes such as career prospects. Thus, mental health difficulties posed a real threat to the young adults with intellectual disabilities in the study.

Forte, Jahoda, and Dagnan (2011) explored the experiences of young adults with and without intellectual disabilities transitioning out of high school. Researchers were interested in whether the transition for individuals with intellectual disabilities was expected to be particularly challenging (in terms of anxiety) given that they often experience specific challenges in the transition; namely, they often experience social marginalization, have fewer career options and rely upon family for support. Fifty-two young adults (17-20 years) took part in the study (26 with mild intellectual disabilities, and 26 typically developing). Individuals with intellectual disabilities reported significantly more worries than typically developing peers, and reported greater levels of feeling distress regarding the transition out of high school. In particular, individuals with intellectual disabilities expressed concerns with being bullied, failing in life, making and keeping friends, and losing someone they were dependent on.

Mental Health Understanding in People with Intellectual Disabilities

While individuals with intellectual disabilities have increased risk of developing mental health difficulties, there is very limited work exploring how they perceive these experiences and the support they may or may not receive. Of the studies that have been conducted, most of them examined the experiences that people with intellectual disabilities have regarding the mental health services they received or prevalence rates rather than the subjective experience of their mental health condition (Chen et al., 2006; Cooper et al., 2007; Reid et al., 2011; Robinson, Escopri, Stenfert Kroese, & Rose, 2016).

An exception is a study by Cookson and Dickson (2010) who explored the experiences of individuals with intellectual disabilities with psychosis. The researchers interviewed eleven adults with intellectual disabilities in a medium secure psychiatric unit about their experiences with schizophrenia and what they understood about their diagnosis. The interviews were transcribed and analyzed using Interpretative Phenomenological Analysis (IPA). In semi-structured interviews, participants highlighted the reality of their symptoms, expressing the realness of their symptoms and the realness of voices that they heard. The participants also discussed how they made sense of their diagnosis throughout their life span and linking past experiences to it. In some cases, participants associated the symptoms they experience to spiritual experiences, while others identified their symptomology as a product of mental illness. The last theme that emerged was the perception of being labelled. Participants expressed that their diagnosis of schizophrenia had been a label given to them by doctors, and their understanding of schizophrenia was grounded in an illness model.

Robinson and colleagues (2016) conducted a study where adults with intellectual disabilities were interviewed about their subjective experiences related to living with psychotic symptoms. The researchers identified three main themes: (a) self-concept, how I understand and

see myself); (b) impact, how having mental health problems and learning difficulties affect my life; and (c) coping, how I cope with my mental health and learning difficulties. When individuals were asked about their labels, they appeared to have limited knowledge and understanding about their labels. Individuals with intellectual disabilities had limited understanding about their diagnosis and label, which impacted them seeking support for fear of negative consequences. Robinson and colleagues (2016) concluded that one of the ways to support individuals with intellectual disabilities who have mental health difficulties is to provide them with psycho-education.

Crowley, Rose, Smith, Hobster, and Ansell (2008) conducted a study where psycho-education was provided to a group of eight adults with mild intellectual disabilities who also had bipolar disorder or schizophrenia. Psycho-education was provided about a variety of topics such as medication adherence, stress and anxiety, early signs of mental health difficulties, and psychosis. Overall, researchers noted that the process of psycho-education appeared to be a positive experience for individuals who participated. Five of the eight who participated in the study had increases in self-esteem. Psycho-education about difficulties related to mental illness also provided a means of empowerment for participants, and allowed them to be more proactive when dealing with mental health difficulties.

Considering that people with intellectual disabilities are at greater risk of developing mental health difficulties, investigating what they understand about mental health, specific their understanding of positive mental health is warranted. Before research and intervention can be designed to address the unique mental health needs of individuals with intellectual disabilities, we must develop a better understanding of what is understood about mental health by individuals with intellectual disabilities.

Mental Health Literacy

Mental health literacy is a concept that has evolved over time. Mental health literacy was initially derived from health literacy. Jorm and colleagues (1997) identified the term Mental Health Literacy, defined as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (p. 182). Mental health literacy is thought to consist of several components, including: the ability to recognize specific disorders or different types of psychological distress; knowledge and beliefs about risk factors and causes; knowledge and beliefs about self-help interventions; knowledge and beliefs about professional help available; attitudes which facilitate recognition and appropriate help-seeking; knowledge of how to seek mental health information.

In the early stages, mental health literacy was considered a tool for recognizing mental disorders (Kutcher et al., 2016) however, over time mental health literacy has become more complex. The World Health Organization (WHO) has identified mental health literacy as key for improving the mental health of individuals and populations as it acts as a social determinant of health (2013). Currently, mental health literacy is a complex, multifaceted term that involves multiple components. Specifically, mental health literacy involves understanding how to obtain and maintain positive mental health; understanding mental disorders and their treatments; decreasing stigma related to mental disorders; and enhancing help-seeking efficacy (Kutcher, Wei, & Coniglio, 2016). Improved mental health literacy helps to facilitate help-seeking behaviour and reduces stigma (Gulliver, Griffiths, & Christensen, 2010). Kutcher and colleagues (2016) reported that young people need to develop a mental health literacy foundation in order to be prepared for the transition into adulthood, and that one of the places that this could take place

is in schools. The World Health Organization (2009) recognizes school as an important platform to address student mental health.

Gulliver, Griffiths, and Christensen (2010) conducted a literature review examining barriers influencing young people's (typically developing) help-seeking behaviour when experiencing mental health difficulties. The literature involved reviewing 15 inquiry-based studies, and seven quantitative studies. One of the barriers identified in the literature was mental health professional's difficulty recognizing symptoms of mental illness. Biddle, Donovan, Sharp, and Gunnell (2007) reported that young adults expressed being unaware of the type of distress they were experiencing was "normal" or not. Young people reported they were aware of distress they were experiencing, but often altered the meaning they attached to their distress in attempts to avoid help seeking behaviour. A lack of insight about what mental health is, particularly what factors might be signs of mental illness, may contribute to a lack of help-seeking behaviour. It is important that people understand mental health, particularly the distinction between positive mental health and what could be a mental health difficulty in order to seek appropriate support when needed.

While there has been an influx in research in mental health literacy, which has begun to impact policies across Canada, such as access to mental health services and training, there is currently no known research about how individuals with intellectual disabilities conceptualize or understand mental health difficulties. Understanding their perspective would be helpful in order to create policies that target vulnerable populations to mental health difficulties, such as individuals with intellectual disabilities.

Positive Mental Health

Positive mental health foundations. One of the factors in mental health literacy is understanding positive mental health, how to obtain positive mental health and how to maintain positive mental health. Mental health promotion is an alternative to treating mental health difficulties and focuses on preventing the development of such difficulties (Keyes, 2013). Mental health promotion targets the whole population; those with positive mental health, as well as those with less positive mental health. Keyes (2013) points out that in order for a shift to take place toward mental health promotion the bias to focus on presence/absence of mental health difficulties must be removed.

Researchers have argued that the conceptualization of mental health should include not only the absence of mental health conditions, but also the presence of positive views of self, feelings, thoughts and behaviour (Hubka & Lakaski, 2013). One of the reasons for the development of this perspective is that targeting mental health illnesses does not always reduce the prevalence of mental health illnesses (Hubka & Lakaski, 2013). Additionally, targeting positive mental health can help make the shift between providing intervention and recovery-oriented services to individuals, to a more preventative approach (McGorry et al., 2013).

Positive mental health has recently gained attention and is considered distinct from mental illness because it encompasses the absence of mental illness, as well as other important factors (Diener, 1984). Keyes' (2002) proposed that mental health and mental illness are separate, but have correlated axes that represent the present or absence of mental health and the presence or absence of mental illness. Barry (2007) explains that positive mental health is integral to a person's overall health and well-being and can lead to lasting effects on health and social outcomes. It has been conceptualized as the basis for individual well-being and functioning (Hall, McKinstry, & Hyett, 2016). In order for a person to recognize if they are

experiencing mental health difficulties, they must first be aware of what positive mental health is. Positive Mental Health is made up of a variety of aspects such as emotional, psychological, social, physical and spiritual well-being (World Health Organization, 2005; Huppert, 2006; Keyes, 2002, 2007; Ryff et al., 2006).

Hall, McKinstry, and Hyett, (2016) explored the perceptions held by three typically developing youth (aged 12-25 years) of positive mental health. The researchers used an interpretive descriptive qualitative study, where their main source of data was with the use of digital stories, which allowed participants to express their perceptions of positive mental health in an interesting and engaging way. The digital stories created by participants were transcribed. Codes and themes that emerged in the data were identified. Five main themes emerged from the data: components of spirituality; occupational factors; aspirations; social influences; and challenges and barriers. Participants expressed that positive mental health was developed through their experiences with mental illness and adversity; and when they were able to increase their coping strategies and resilience. Spirituality was recognized by participants as presenting opportunities to formulate their identity – with participants linking a strong sense of self and self-acceptance to positive mental health. Participants also expressed that aspects of positive mental health included having positive relationships with friends and family, spending time doing things they enjoyed and having aspirations and hope for the future.

Positive mental health conceptualized. Positive mental health is not synonymous with “average” mental health. In order to define it, a distinction needs to be made about trait positive mental health and state positive mental health (Vaillant, 2012). Suldo and Huebner (2006) noted that the absence of mental health is not equivalent to the presence of mental health. Additionally, positive mental health must be understood within the context of the individual. Everyone has the

capacity to develop positive mental health and to enhance it even if they are experiencing a mental illness (Mental Health Commission of Canada, 2012). Tudor (1996) notes that mental health has almost as many definitions as researchers. This poses a problem when trying to understand positive mental health and factors that promote it. Hall, McKinstry, and Hyett (2016) point out that while there has been an increase in attention toward young people's mental health, there is still a lack of qualitative description provided by young people themselves about this concept. If researchers hope to target young people through positive mental health programs, they must understand how they understand concepts such as mental health, and the impact it can have on their daily lives.

In order to best understand how positive mental health is conceptualized in Canada, definitions were explored within Canadian mental health initiatives. Specifically, the Public Health Agency of Canada (2014) defines mental health as:

The capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice, interconnections and personal dignity (p. 3).

This definition is holistic, distinct from mental illness, and representative of positive mental health. Additionally, the definition and components of mental health provided by the Public Health Agency of Canada can be used to further operationalize positive mental health. The ability to enjoy life, dealing with life's challenges, emotional and spiritual well-being, and social connections is explored in more detail to further conceptualize their importance, and how they relate to individuals with intellectual disabilities.

The ability to enjoy life. The ability to enjoy life is one way to operationalize positive

mental health. Life satisfaction, happiness, and subjective well-being are all concepts that have been used as a proxy for the ability to enjoy life (CIHI, 2009). Suldo and Huebner (2006) explored the relationship between life satisfaction and adaptive functioning in adolescents. Life satisfaction is a component of happiness, often referred to as subjective well-being. The researchers conceptualized life satisfaction as “as a cognitive, global appraisal that people make when considering their contentment with their life as a whole or in regard to specific domains of life such as family, environment, friends, and self” (p. 180). In this study, researchers asked 98 students from three middle and two high schools about student life satisfaction (using the Students Life Satisfaction Scale (SLSS: Huebner, 1991). Researchers found that high levels of life satisfaction to be a predictor of seven positive indicators of social, intrapersonal, and cognitive functioning. Additionally, youth who had high levels of life satisfaction scored lowest on measures of behavioural and emotional problems. Adolescents that identified as having average and high levels of life satisfaction had significantly lower levels of psychopathology symptoms (including, anxiety/depression, somatization, withdrawal, delinquency, and aggression). This study illuminates the importance of life satisfaction as a predictor of positive psychosocial factors which can act as a protective factor from the development of mental health difficulties.

Italian researchers, Addabbo, Sarti, and Sciulli (2016) investigated what factors contribute to feelings of life satisfaction amongst individuals with intellectual disabilities, based on the understanding that analyzing the source of what the sources of disadvantage are can lead to high levels of life satisfaction. 3,121 people with disabilities completed surveys which explored life-satisfaction and variables such as demographics, house hold structure, economic status, health, and friend relations. Life-satisfaction was positively related to family relative

relationship, friend relationship, economic conditions, and leisure time. These findings suggest that relational factors, stable socio-economic status and spending time participating in enjoyable task all contribute to life satisfaction for individuals with disabilities.

Dealing with life's challenges. Dealing with life's challenges is another factor that makes up positive mental health. Coping with life's challenges involves making a conscious effort in times of stress to regulate one's emotions, thoughts, behaviours and physical health, as well as their environments (Compass et al., 2001). There are a number of life circumstances linked to higher levels of life enjoyment: self-perceived health, higher levels of social support, higher levels of trust of others, and feelings of control in one's life (Helliwell & Putnam, 2004; Milan, 2006).

Another aspect of dealing with life's challenges is resilience. Resilience is a complex term which differs depending on the context and definition. While there are many ways to conceptualize resilience, the Canadian Public Health Agency (2014) conceptualizes it using Mangham's (1995) definition, "resilience is the capability of individuals and systems (families, groups, communities) to cope successfully in the face of significant adversity or risk. This capability develops and changes over time, is enhanced by protective factors within the individual/system and the environment and contributes to the maintenance or enhancement of health" (p. 2). Resilience also can involve a person's ability to seek out help. Ungar (2008) conducted a study which looked at adversity management among youth. Youth were more successful at navigating adversity when they had available resources and opportunities to access them. Resources included having a supportive family, community and peer connections; feeling a sense of purpose; perceiving the ability to make change; adhering to cultural practices; and having a meaningful role in the community (CIHI, 2009).

Hall and Theron (2016) explored resilience in youth with intellectual disabilities. They explained that while there are a number of risks associated with having an intellectual disability, some youth are able to cope and demonstrate resilience despite such risks. They were interested in exploring the resilience of youth with ID. In order to do this, researchers interviewed 24 adolescents about their experiences with resilience. In order to be eligible to participate in the study, participants needed to be considered “resilient” based on a panel who deemed resilience as factors such as staying in school, acquisition of life skills, appropriate social behavior, acceptance by peers and/or stable friendships, general emotional stability, and participation in extramural activities. Interviews and drawings completed by participants highlighted the importance of social relationships with parents, caregivers, siblings, teachers and community-based staff. The network of support described by participants became helpful for resilience because it provided them support to regulate behaviour and emotions, offered safe places to learn and develop, encouraged them to practice and master daily challenges and their capacity to be independent and make their own decisions. This study highlights the importance of social supports with this population as a way to develop resiliency in the face of adversity.

Emotional well-being. A positive sense of emotional well-being is another component of positive mental health, which involves both experiencing emotions and regulation of emotions (CIHI, 2009). Emotional well-being involves “experiencing positive emotions and regulating them in such a way that benefits are maximized, and potential negative aspects are limited” (Public Health Agency of Canada, 2014, p. 14). Fredrickson and Joiner (2002) explained that positive emotions include joy, interest, contentment, and love. Fredrickson’s (1998) model of positive emotion, *broaden-and build theory*, posits that positive emotions encourage people to seek out experiences that lead to upward spirals in emotion, by broadening emotion and

cognition. Unlike negative emotions which lead to downward spirals and narrowed pessimistic perspectives, positive emotions lead to an increase in positive emotions. In order to assess this theory, researchers conducted a study where they examined if positive emotions predicted broadened ways of thinking, which could lead to increases in positive emotions; and in contrast, if downward spiral thinking patterns can lead to narrowed perspectives, which then can lead to increase in negative emotionality (a reciprocal relationship). One hundred thirty-eight college students completed self-report measures of affect and coping five weeks apart. The regression analysis indicated that participants who showed initial positive affect predicted broad-minded thinking and coping, consistent with *broaden-and build theory*. This theory emphasizes the importance of positive emotions, and their lasting impact on positive mental health.

Conder, Mirfin-Veitch and Gates (2015) investigated risk and protective factors for women with intellectual disabilities aged 21-65 years old for mental health and well-being. Twenty-five women from New Zealand were interviewed by researchers regarding their life, childhood, and their experiences related to mental health. When participants were asked what factors helped to keep them mentally well, they spoke about three main themes. First, most participants emphasized the importance of close relationships to their mental health. Positive relationships with family and friends were identified as a major source of happiness for women being interviewed. Women expressed that when they were not close to family, friendships were particularly important to them. Another theme that emerged in the data was the concept of “keeping busy.” Women expressed that they spent time working or volunteering through work experiences with school and other agencies. Involvement in these opportunities provided a sense of purpose for participants. Additionally, the researchers reported that despite difficulties, the women demonstrated incredible perseverance and willingness to seek job opportunities. The last

theme identified by the researchers was that feelings of autonomy and happiness, which were related to overall well-being. Experiencing positive emotions, being happy, and smiling were considered very influential for mental well-being according to participant reports.

Spiritual well-being. Another factor that is associated with positive mental health is spiritual well-being; that is, feeling connected to something larger than oneself as well as having a sense of purpose (CIHI, 2009). Spiritual well-being has been documented as a predictor of positive mental health in adolescent and young adult populations (Compton, 2001; Lewis, 2001). Specifically, Wong and colleagues (2006) explored the relationship between spiritual well-being and mental health in adolescents in a literature review. Researchers defined spiritual well-being in terms of religiosity and spirituality. Religiosity is often referred to as a person's relationship with a faith tradition or doctrine, while spirituality is often related to a person's belief in the intrinsic human capacity for transcendence, embedded in something great than oneself (Wong et al., 2006, p. 163). In order to conceptualize mental health, researchers took a holistic perspective of mental health; that is focusing on mental health difficulties as well as positive mental health. The literature review included 20 studies exploring the relationship between religiosity and spirituality with mental health.

Liu and colleagues (2014) were interested in examining how young people with intellectual disabilities or autism experience faith, and spiritual expression. In order to investigate this, researchers interviewed 20 participants between the ages of 13 and 21 years. Participants expressed the importance of faith in their lives and how the practices they adopted (such as prayer, particular beliefs, congregational activities and social connections) had a positive impact on their lives. They also highlighted the importance that faith provided for them in terms of social connectedness. Participants expressed a sense of belonging and being treated well in the

faith communities that they identified with. Faith involvement also provided participants a place where they expressed feelings of being known and understood, as well as accepted for who they were.

Social connections. Another important factor related to positive mental health is being socially connected. Respect for one's culture, for equity, social justice, and personal dignity are factors identified as being important for positive mental health (CIHI, 2009). Hall-Lande and colleagues (2007) looked at indicators of positive mental health of a group of 4746 adolescents. Students who reported feelings of social isolation has higher levels of depressive symptoms, lower levels of self-esteem and elevated odds of suicide attempts, compared to students who did not report feeling socially isolated. Alternatively, feelings of connectedness with peers, school and family acted as protective factors. This study highlights the important role that peers, and family can play in the positive mental health of adolescents.

Gilmore and Cuskelly (2014) explained that loneliness has been identified as a significant predictor for a range of physical and mental health challenges, including a review of how loneliness impacted children and adults with intellectual disabilities. The researchers explained that current literature suggests that about 50% of individuals with intellectual disabilities are chronically lonely (Heinrich & Gullone, 2006). This research highlights the difficulties that individuals with intellectual disabilities can have with developing friendships. The researchers explained a theoretical model of vulnerability, which is comprised of three reciprocally influencing domains that influence loneliness in this population: social attitudes and expectations, opportunities and experiences, and skills deficits. Social attitudes and expectations involve how individuals are related to. Unfortunately, while there has been a shift in inclusivity, many people still have reservations about interacting with individuals with intellectual

disabilities, making it a stigmatizing characteristic (Scior, Potts, & Furnham, 2013). Individuals with intellectual disabilities often have less opportunities and experiences, segregating this population (Gilmore & Cuskelly, 2014). Lastly, the characteristics that individuals with intellectual disabilities have may contribute to their feelings of loneliness. Social relationships require communication, perspective taking, attention, self-regulation and other complex tasks. Individuals can have difficulties in these areas, which can make social relationships difficult (Gilmore & Cuskelly, 2014).

Purpose and Research Question of the Present Study

The purpose of this study was to explore how young adults with intellectual disabilities understand the concept of positive mental health by exploring how individuals conceptualize and experience their mental health in the world, and their experiences related to positive mental health. The research question that the researcher examined was: What are young adults with intellectual disabilities perceptions of positive mental health?

Chapter 3: Methodology

Overview

In order to investigate the proposed research question, the researcher interviewed individuals with intellectual disabilities to explore their understanding of positive mental health using an inquiry-based methodology, specifically, phenomenography. In this chapter theoretical foundations, the researcher role, research contexts, data sources, and data analysis are presented.

Theoretical Foundations and Methodological Approach

This research project was framed within the interpretivist theoretical position, using the phenomenography methodology. An interpretivist theoretical position was chosen because the current study was focused on understanding how individuals with intellectual disabilities conceptualize positive mental health, based on their interpretations of the world and their experiences. There are a number of underlying assumptions in the interpretivist theoretical position which impact the way research is approached. In interpretivism, the nature of reality is assumed to be socially constructed. The goal of interpretivism is often to understand something (for example, a story or a phenomenon) – with less emphasis put on predicting causal relationships between variables.

Svensson (1997) outlines the theoretical perspective of the methodology of phenomenography, and the underlying assumptions that are made regarding the nature of conceptions. In this methodology, knowledge is assumed to be based on one's thinking, which is created through human activity. Svensson (1997) explains that knowledge is based not only on one's own thinking, but that it is also dependent on the external world which thinking is directed toward. In contrast to positivistic assumptions, concepts are dependent on a person's external world, human activity, and an individual's thinking.

Phenomenography was employed in order to explore how individuals with intellectual disabilities understand the phenomenon of positive mental health. Phenomenography is a research approach that seeks to understand the way in which people understand, conceptualize, and experience a specific phenomenon in the world, thereby describing the categories of description that emerge from the data, as referred to as an “outcome space.” This methodological approach involves categorizing descriptions of a specific phenomenon (in this case, positive mental health), and then explaining and exploring the various dimensions of said phenomenon, which are usually organized hierarchically. Individual’s perceptions of phenomena vary, which results in a number of descriptive categories and explanations for positive mental health. According to this methodology, there are a limited number of categories of description; that is, there are only a certain number of ways participants describe a concept.

Phenomenography is a research approach that aims to describe the different ways a group of people understands a phenomenon (Marton, 1981). The investigation was focused on the variation that exists in how people experience the phenomenon. Phenomenographic studies focus on both what people think of a particular phenomenon (that is, what is “thought of”) and what they have experienced related to the phenomenon (“that which is lived”; p. 180). The goal of phenomenography is to understand or conceive a specific phenomenon, as opposed to phenomenology, which aims to clarify the structure and meaning of a phenomenon (Giorgi, 1999). This specific methodology was chosen because it seeks to better understand people’s understanding of a specific phenomenon (in this case, positive mental health) and because it focuses on both the conceptual understanding of a phenomenon, as well as how a person has experienced the phenomenon (Marton, 1981).

Researcher Role and Potential Bias

The research project took place at an independent living program where the researcher had previously worked. Therefore, the researcher had an established relationship with the staff and some participants in the program. However, the researcher had not worked at the site on a regular basis for nearly two years. In order to address any challenges that could emerge from the researcher's past involvement (Alvesson; 2003), the researcher had conversations with the program staff and participants to establish her role as a researcher. Participants and staff were also encouraged to provide feedback or questions throughout the process. Before interviews were conducted, the researcher individually met with each participant to go over the consent process as well as to address any questions that participants had.

Due to a previous relationship that the researcher had with some of the participants, one potential bias that was identified while doing research was anticipating the response level and depth by some participants. In the researcher's previous role at the program she worked as a program facilitator and taught life skills to program participants. This allowed her to get to know participant's individually and have insight into their level of functioning. Given that the researcher knew some participants from her past role, she worked to remain impartial while interviewing individuals she knew. Additionally, while interviewing she paid attention to any expectations she had of participants. Table 1 provides more information about participant characteristics, including whom the researcher had past relationships with.

Special consideration was paid to respecting the time and resources of the program because it was understood that they were allowing the researcher to enter their environment and conduct research. When the research project is completed and reviewed by the supervisor committee, the researcher will share the findings and collaborate with the program staff about how findings can be integrated within the mental health curriculum that the program implements.

Another concern that was addressed in the current research project was ensuring to listen to the voices of individuals with disabilities, rather than assuming or answering for them. Coons and Watson (2013) report that when conducting research with individuals with intellectual disabilities, the research is predominantly controlled by people who do not have a disability (Kitchin, 2000). Due to this, researchers in the disability field have suggested that research is not always representative of the people's experiences. Scholars have struggled with the notion that past research has been research-oriented not client-oriented, and therefore it may further reinforce exclusion of individuals with intellectual disabilities. The researcher addressed this in the current study by directly involving individuals with intellectual disabilities as participants, engaging and interacting with them before data collection to help facilitate trust and relationship building and seeking to understand their unique experiences and perspectives. This main purpose of the study was to learn about individual's understanding of positive mental health by asking the individuals with intellectual disabilities directly, rather than relying on third parties.

Research and Ethics Approval

Ethics approval was obtained through the University of British Columbia Behavioural Research Ethics Board (BREB). The research conducted aligned with ethical guidelines outlines by the BREB. In addition to obtaining informed consent from the participants, the researcher worked to anticipate ethical challenges and strove to be aware of options for handling them, in an ethical manner.

The documents were written at a developmentally appropriate level (mid-elementary reading level). Additionally, a simple paraphrase about the goal, method, duration, potential risks and benefits of participating in the study, as well as the informants' rights to refuse to participate was orally reviewed by the researcher individually with each potential participant. In addition to

a longer consent, a shorter more developmentally appropriate version accompanied the longer consent letter. The researcher worked to clearly explain the concept of voluntary participation with the participants, by providing opportunities for member checks (to ensure understanding) and involved program staff members to help explain and inform participants. Given that many of participant's past experience was when the researcher was in a staff role several years ago, the researcher explained that she was no longer a staff member, and that participation in the research was completely voluntary (and not part of program curriculum). The researcher also met with her research supervisor on an ongoing basis in order to ensure research was conducted to the highest ethical standard. Lastly, the researcher kept a researcher journal to record any challenges, thoughts, or biases noticed in herself.

Participants

Recruitment. Participants were recruited from an independent living program in central Canada. Participants were told the general purpose of the study and asked if they would like to participate. Participation in the study was completely voluntary. In order to gain permission to conduct research at this program, the researcher provided the program with formal documentation that the research had been approved by the BREB. In addition, the program was provided a detailed description of the goal and logistics surrounding the current research project, including the interview questions that the participants were asked. The participants in the program were also informed about the current project, and the researcher explained the goal of the project, how much time involvement it would take, and address any question that participants had. The description of the research project was presented verbally and in writing to ensure optimal understanding of the project before providing consent. Before deciding to participate in the study, participants were encouraged to discuss their involvement in the project with program

staff and their parents/caregivers as applicable. If program participants decided they wanted to participate in the study, they were asked to provide informed consent by signing an informed consent form.

Independent living program. Participants were recruited from an independent living centre in central Canada. The purpose of this program was to teach skills to participants to one day live independently. The program provided support for skill development including psycho-education about mental health. Participants worked in group settings with staff to develop skills in areas such as money management, cleaning, cooking and job skills. Additionally, participants had group lessons about the importance of physical and mental health. In order for participants to join the independent living program they were assessed by an occupational therapist to determine potential to live independently. Participants were required to have potential to live independently or semi-independently to join the program. Most participants who attended the program had been previously diagnosed with a mild to moderate intellectual or with autism spectrum disorder.

Selection. Inclusion criteria for participation in the current study was established before the recruitment process began. The phenomenographic method involves selecting participants who have diverse backgrounds – the more diverse a set of responses, the more variability of perceptions of positive mental health. Therefore, the researcher used the following criteria to select participants:

1. English-speaking.
2. Between the ages of 21 and 30 years.
3. Diagnosed with a social or intellectual disability by a trained and appropriately credentialed professional.
4. Did not require one-to-one support in the community or in daily living.

5. Had long term plans (and potential) to live independently or semi-independently in the community.
6. Had the ability and legal authority to provide informed consent.

The sample met recommendations by Marton and Booth (1997) – that sampling should focus on capturing diversity, rather than seeking to produce a statistically balanced representation of participants. Bowden (2005) and Trigwell (2000) suggest that there is not a prescriptive sample size for phenomenographic studies, however diversity of experience and feasibility must be considered. In accordance with this recommendation provided, the researcher interviewed 8 participants, and sought to allow for a diverse sample of participants and experiences.

Table 1: Characteristics of Participants

Pseudo name	Sex	Age	Currently Employed	Previous Relationship?
James	Male	21	No	Yes
Kyle	Male	24	Yes	No
Steven	Male	24	No	Yes
Sarah	Female	29	No	Yes
Rick	Male	22	No	No
Henry	Male	28	Yes	Yes
Kevin ¹	Male	22	Yes	No
Zack	Male	28	Yes	Yes

¹ an exception was made if participants were able to provide legal guardian consent.

Data Sources

Semi-structured interviews. Data was gathered primarily through semi-structured interviews, where individuals were asked to describe their interpretation of a phenomenon – in this case, the phenomenon of positive mental health (Marton 1988). Before interviews began, the researcher spent time with each participant to establish rapport and address questions. The participant interviews were audio-recorded, with the consent of the participants, and transcribed. Each interview took approximately 30 minutes to 45 minutes. In the interviews, participants were encouraged to talk about their experiences about positive mental health and were asked to give concrete examples (Larsson & Holmstrom, 2007). See Appendix A for the interview questions.

Follow-up interview. In order to provide more insight into participants views of positive mental health, follow-up interviews were conducted which explored and clarified

participant's reports. After reading through each interview transcript, the researcher highlighted areas within the interview that were not clear and scheduled follow-up interviews with willing participants.

Drawings. To encourage conversation, the semi-structured interview also included an opportunity to draw a picture(s) (i.e., participants were asked to draw what participants believe help to contribute to their positive mental health). It was anticipated that participants may have difficulty expressing themselves through words, particularly when asked about an abstract concept such as positive mental health. The symptomology of intellectual disabilities may be associated with limited expressive language skills (Emerson & Baines, 2011) and therefore one of the ways to compensate for this potential limitation was to provide another form of data collection that did not solely focus on verbal dialogue. Hall and Theron (2016) used this approach as they explored adolescent's experiences with resilience using drawings. They expressed that allowing for a visual component facilitated rich data and was able to help compensate for expressive language related limitations associated with intellectual disabilities.

Drawings were used as a means of elicitation, specifically participants were asked to draw pictures about what factors they believe contribute to positive mental health and discuss their drawings (see Appendix B for the drawing script). Not all participants opted to take part in the drawing activity (6 out of 8), however, those that did participant appeared to enjoyed it. The researcher provided necessary prompts and questions to facilitate the drawing process. Once drawings were completed, the researcher asked participants to describe their drawings to the researcher and facilitated a discussion about positive mental health to further understand participant's perceptions of positive mental health. The conversations that took place surrounding the drawings were recorded and transcribed. While the drawings themselves were

not analyzed, the conversations that took place around them were included in the data that was analyzed.

Reflective journal. In order to ensure rigour, a reflective journal was kept to record thoughts, insights, decision-making points, and follow-up items that came up while conducting the study. Additionally, emotions, information of interest, and events were recorded in the journal so that the researcher could identify any personal biases that may have arisen throughout the study and remember important information. The reflective journal was also used to record first impressions about emerging themes within the interviews and how they may relate to each other. The researcher referenced the reflective journal throughout data analysis in order to compare current interpretations, with impressions that occurred while collecting data. The information in the journal served as contextual information in interpreting the data from the interviews and drawings but was not systematically coded and analyzed.

Ensuring Rigour

Overview. To ensure that the data collected was credible and reliable, the researcher implemented a number of strategies in order to ensure the rigour of the data. A team approach was used when analyzing the interviews in order to ensure the trustworthiness of the data. Additionally, multiple sources of data were examined, member checks were employed, and a follow-up interview was implemented (see Appendix C).

Team approach. To ensure that the researcher objectively and accurately analyzed the data, the researcher worked within a team framework (Bowden, 2000; Dall’Alba, 2000). Given the nature of this research project, the researcher primarily collected the data individually, however, to allow for data trustworthiness, the researcher collaborated with others during the data analysis phase of the research. Specifically, when the researcher had identified categories of

descriptions within the data, they were discussed with other researchers. The researcher outlined a detailed account of the methods of decision making they used when deciding on categories to the research team, which helped to promote the validity and reliability of the study (Merriam, 2002).

Specifically, the researcher worked with another researcher who read through each transcript and evaluated coding decisions. After the secondary researcher had read through each transcript (that was already coded), both the primary researcher and secondary researcher met to discuss any discrepancies between the way in which the data was coded. The primary researcher integrated the secondary researcher's feedback. In addition, the researcher checked in with her supervisor to discuss ideas and decisions throughout the process.

Triangulation. Triangulation was an important component to build into the research design because it enhanced the credibility and validity of research, specifically data triangulation and methodological triangulation was built into the current study. Multiple sources of data (including participant interviews, drawing, and the researcher's journal) were examined to evaluate if the data converged, was discrepant or contradicted each other. Each of these outcomes provided valuable insight into the phenomenon that was being explored – discrepant or contradictory data led to new insights or perspectives

Member checks. The researcher conducted member checks with participants during the interview process and checked in with participants to ensure that the researcher fully understood what they were trying to communicate. For example, the researcher summarized what the participant had said and asked them if that is what they meant.

Follow-up interview. After the data was transcribed, and primary categories were identified within the data, follow-up interviews were conducted. If participants wanted to take

part in the follow-up interview process, the researcher met with them in person and asked them pertinent follow-up questions (see Appendix C). Five of the eight participants agreed to participate in follow-up interviews.

Data Analysis

Phenomenographic analysis involves identifying similarities and differences within the data and sorting them into categories (Marton, 1994). Interviews from participants were analyzed to identify categories of descriptions described by participants that capture how individuals with intellectual disabilities understand and describe positive mental health. The data was viewed holistically, in order to capture a rich understanding and pattern of description of positive mental health, as explained by participants. Drawings, entries in reflective journal, and observations were used to further understand and conceptualize participant's description of positive mental health by providing opportunities to elicit responses and recording initial impressions and interpretations about emerging themes in the data. The Åkerlind's (2005) method was used in order to analyze the data. This method was derived from work by Dall'Alba (1994), Bowden (1994) and Prosser (1994). The goal of this approach was to view transcripts holistically and retain the overall meaning of significance of each transcript (Forster, 2016).

Step 1. After all interviews had taken place, the researcher transcribed interview data and read each interview individually three times in order to become familiar with it. On the third reading, the researcher began to make notes on each transcription, highlighting key difficulties or themes that emerged.

Step 2. After the researcher had become familiar with the data – gaining a depth and breadth of understanding of the data through a careful review of the transcripts– the interviews were sorted into similar categories.

Step 3. Next, after spending more time reading, focusing on searching for similarities and differences in the overall meaning of the transcripts, the researcher re-arranged the groups of transcripts and sorted them into similar categories. When there were differences in how the positive mental health was described the term “dimensions of variation of awareness” was used (Åkerlind, 2005, 122).

Step 4. The differences and similarities were further sorted into themes. After data had been sorted into similarities and differences of description, the researcher assigned categories of description to the sorted themes. Categories of description represented different ways of experiencing positive mental health.

Step 5. One way to ensure rigour and trustworthiness of the data was to consult with other researchers about the interpretation of the data. The researcher sought external verification from other researchers about the conclusions she was drawing from the data. The researcher reviewed the transcripts with other researchers and communicated about decision making rules.

Step 6. Once the researcher had assigned categories of descriptions to the overall transcripts, they were presented in a diagram. The final product created the outcome space, which provided a diagrammatic representation of the categories of description identified by the researcher and expressed by the participants. Åkerlind (2005) defines outcome spaces as ‘a way of looking at collective human experience of phenomena holistically’ despite the variation in the perception and experience of the phenomena. Outcome spaces “represent the full range of possible ways of experiencing the phenomenon in question, at this particular point in time, for the population represented by the sample group collectively” (323).

Summary

The current study sought to gain a better understanding about individuals with intellectual disabilities understand of the phenomenon of positive mental health, employing the phenomenographic methodology. The researcher's goal was to understand and conceptualize how individuals with intellectual disabilities understand positive mental health using semi-structured interviews and using elicitation devices such as participant drawings. Special attention was being paid to ensuring that participants understood what was involved in participating in the study and highlighting their experiences and perceptions of positive mental health.

Chapter 4: Findings

Overview

The purpose of this study was to gain a better understanding about how young adults with intellectual disabilities understand the concept of positive mental health by exploring how individuals conceptualize and experience their mental health in the world, and their experiences related to positive mental health. The research question of interest was: What are Young Adults with Intellectual Disabilities Perceptions of Positive Mental Health? The findings in this chapter are summarized by categories of description identified through analysis of the semi-structured interviews. The current research project highlighted that participants responded to this research question in four main ways (known as categories of description). A visual summary (Outcome Space) of participant's categories of description is presented below, and each category and subcategory are explained in detail.

Perspectives of Individuals with Intellectual Disabilities

Individuals with intellectual disabilities shared in-depth and detailed descriptions of their understanding of positive mental health. Interviews were categorized based on content, with individuals identifying similar descriptions for the concept of positive mental health. Specifically, individuals described positive mental health in relation to physical health. When participants described positive mental health related to the physical health, some explained that positive mental health was synonymous to being physically healthy and that ways to be “healthy” were eating health foods (e.g. fruits and vegetables) and exercise. Other participants explained that physical health was a contributor to positive mental health. Another category involved recognizing positive qualities in the definition of positive mental health. Two subcategories were derived from positive qualities – happiness and positive actions. Another

category that emerged was participant's explaining they were unsure about the definition of positive mental health. Mental illness was another category described by participants. Two subcategories were identified within the category of mental illness, specifically, presence of mental illness and absence of mental illness. These emergent categories are discussed below with descriptions of the categories and the illustrative quotes.

Figure 1: Outcome Space 1

Overarching Categories of Description

Category 1: Physical health. Participants highlighted physical health as part of their definition of positive mental health. When asked to describe what positive mental health was, many participants highlighted the importance of physical health. Some expressed that physical health and positive mental health were the same, while others said that being physically healthy could contribute to positive mental health.

Subtheme 1.1: Synonymous. The majority of participants who discussed physical health in their definition of positive mental health said that being healthy was the same thing as positive mental health. Upon follow they said that physical health and positive mental health were the same thing. Some participants did not distinguish positive mental health from body health, but rather saw the two as synonymous. Eating healthy and going to the gym were factors for having physical health, which was expressed to be the same thing as positive mental health. For example, when asked about what their understanding of positive mental health was one participant stated that it was related to taking care of one's body, and one way to do that is eating fruits and vegetables at every meal and going to the gym. One said "... you need to take care of your body basically.... you need to eat fruits and vegetables at every meal basically." Another participant said that mental health involves staying in shape, and that staying in shape involves working out and eating healthy, "doesn't it mean that umm. staying like in good shape.... It means like working out in the gym and all. You know, eating healthy and all." Another discussed being physically sick and taking insulin. When asked about positive mental health he said it "means they use insulin." He elaborated that it means you are "diabetic and stuff, like my uncle and my friend." Upon additional follow-up, the participant said that positive mental health involved eating healthy and that he did not believe there was a difference between positive mental health and physical health. Specifically, he described a mentally healthy person by saying "they eat healthy stuff...like apples, peaches, bananas." When asked if there was a difference between positive mental health and physical health he said, "not really no... cuz you're healthy".

Subtheme 1.2: Contributor. Some participants highlighted the importance of physical health as a contributor to positive mental health. When asked if there was a distinction between positive mental health and physical health a participant discussed how physical health can impact

mental health also that positive mental health and physical health are separate but could impact each other.

I've never really had too many physical health problems, but I'm pretty sure that physical health could affect Mental Health... like if someone breaks their leg they may start yelling or that sort of stuff because it's so painful. It's really complicated. People can get scared of it happening again, or just have bad memories of being hurt. That's an example of how physical health can affect Mental Health.

Category 2: Unsure. Some participants were unsure of the definition of positive mental health. They expressed that they were unsure what positive mental health was or qualified the statements they made by telling the researcher that they were not sure if their answer was correct. One participant, when asked what their understanding of mental health was, responded: “What's it mean? I don't know. What's the question? I beg your pardon.” Another, while providing his definition of positive mental health, expressed uncertainty.

Um that is actually a great question, I say that mental health probably means, just trying to think ... it means that basically making sure that you... ugh that is really hard to say. Does like mental health mean basically making sure that you are healthy and in perfect shape and all? And making sure that you ummm have a good and healthy body.

These quotes illustrate that some participants did not understand what positive mental health was or appeared to be hesitant to provide an answer.

Category 3: Positive qualities. Positive qualities were another category that emerged in participant interviews about the definition of positive mental health. Participants highlighted that positive mental health involved feeling good things (specifically, happiness) and engaging in positive actions (including coping strategies and helping others).

Subcategory 3.1: Happiness. Participants expressed that happiness was part of the definition of positive mental health. Some participants recognized that engaging in positive qualities contributed to positive mental health, while others said that it was synonymous with positive qualities (e.g. positive mental health = happiness). When asked to describe a person with positive mental health, one participant responded that that person “would be happy”. They elaborated by saying they would know that person had positive mental health because “...they're smiling, their eyes are open, they're nice.” Another participant expressed that an individual with positive mental health would be “cheerful and happy.” Yet another participant highlighted happiness as a contributor to positive mental health.

I think that being happy contributes to being mentally healthy because if you're not happy people might think there's something wrong with you and ask you what's wrong. And maybe there are other thoughts going on in your head that you can't really get out of your head of a bad experience or something.

Subcategory 3.2: Positive actions. Participants also included positive actions as part of their definition of positive mental health. Two elements of positive actions were coping skills and helping others. Participants expressed that coping skills were a component of positive mental health, indicating that thinking about good things and being in the moment were components of positive mental health. When asked about positive mental health one participant said:

Well things aren't exactly like all good but I try to think about good things even when things aren't exactly okay or if I am feeling a certain way and I don't cause I don't want the bad things to come out cause then I will say things or do things to other people that might hurt them and I don't want to or later I'll regret it and make me feel really bad.

When asked how the individual was able to focus on the good, they said that part of it involved being in the moment.

You gotta live in the moment and stop like thinking about what is going to happen if I do this or do that... sometimes you just have to make choices even if they are good or bad choices. You might get in trouble for it. You still need to think about a way to deal with that situation.

Category 4: Mental illness. The last category that emerged involved describing positive mental health as related to mental illness. Some participants described positive mental health as being mentally ill, related to suicide, or experiencing symptoms of mental health difficulties. On the other hand, some participants discussed their recognition that positive mental health involved overcoming mental health difficulties.

Subcategory 4.1: Presence of mental illness. For some participants, positive mental health involved mental illness or symptoms of mental health difficulties. When asked about positive mental health one participant expressed “mental health is like an illness basically. Basically, it's about people that actually kill themselves is that right? It's like a disease, right? I'm trying to think what else.” Another participant shared that mental illness can be caused by positive mental health.

Mental health, it's complicated. It is a complicated definition. Basically, it's what you feel and what you do and how it's controlled by your brain and sometimes mental health causes mental illness and sometimes the person feels more powerful than themselves.

Subcategory 4.2: Absence of mental illness. In contrast, some participants described positive mental health as the absence of mental health issues or illness. One participant described

a person with positive mental health as someone where “mental illness is not a problem for them”. When asked to provide more detail about their understanding of positive mental health, this individual explained:

Mental health basically means your health, your feelings, and stuff, like feeling anything and mental health issue is when you have trouble feeling certain things. It is really complicated. Mental health is like the health that kind of controls you in general. And mental health issue is when you have trouble with that thing.... it’s complicated. I don't know. Well I think being happy is like being cheerful that sort of stuff and being mentally healthy means you don't really have mental problems. You don't have big mental problems, that sort of stuff.

Another participant explained that positive mental health involved overcoming mental health difficulties. Specifically, this participant shared that he was able to overcome (or fix) his own mental health difficulties. He explained that he used to be nervous about that he would lose his wallet and that in order to “fix it” he put his wallet in the “right place” and that way he would not forget its location. He shared that this made him feel “smart, nervous and relaxed.” When asked to described positive mental health, he elaborated that it meant “trying to fix the problems, trying to be a mature adult you know”.

Summary

The results of the study revealed a number of categories of description when explaining positive mental health. For participants, physical health, positive qualities, unsure, and mental illness were categories used to describe positive mental health. The results of the study highlight the diversity of participants responses, while also suggesting that responses can be conceptualized as falling in four main categories.

Chapter 5: Discussion

Overview

The primary purpose of the current study was to understand young adults with intellectual disabilities conceptualization of positive mental health. Findings revealed a number of categories that participants used to describe the concept of positive mental health. In this chapter, research that is relevant to the categories of description identified is integrated and discussed. Implications of the findings for school psychologists and mental health clinicians working with individuals with intellectual disabilities are also discussed. Finally, the limitations, strengths, and directions for future research are presented.

Findings of the Present Study Connections to Previous Literature

Overview. Chapter Two provided an overview of the literature related to individuals with intellectual disabilities and their understanding of mental health. One of the key ideas that emerged through the literature review was that there is limited research related to how individuals with intellectual disabilities understand the concept of mental health. Of the studies that have been conducted, most focus on the prevalence rates of individuals with intellectual disabilities with mental health issues (Chen et al., 2006; Cooper et al., 2007; Reid et al., 2011; Robinson, Escopri, Stenfert Kroese, & Rose, 2016). Therefore this study provided new insights into how individuals with intellectual disabilities conceptualize positive mental health. This study uniquely worked to hear first-hand from individuals with intellectual disabilities. In the sections below each category of description provided by the participants and their relevance within the literature are discussed.

Physical health and relevant literature. The first category of description discussed in Chapter four involved positive mental health being described related to physical health. Some

participants described physical health as synonymous with positive mental health, while others explained that physical health contributes to positive mental health. This provides us with insights about how positive mental health is conceptualized by this population. It appeared throughout interviews that some participants heard the word positive mental health and described the word “health.” In short, “positive mental health” and “health” appeared to be synonymous to some participants. The researcher hypothesized that this may be due to the fact that participants were more familiar with this word. Additionally, the idea of physical health is a more concrete and tangible idea compared to positive mental health. This is consistent with previous research that highlights that individuals with intellectual disabilities typically have difficulty with metacognitive skills, including abstract thinking (Sturmey, 2004). One hypothesis is that individuals who were interviewed gravitated towards the concept of “health” as it was more concrete and less abstract. For example, throughout one interview, when the participant was asked to describe positive mental health he explained that it was related to diabetes. When the researcher asked for clarification, it became clear that he was explaining the word “health.” This is important to recognize, as mental health is often considered an abstract concept not only to those with intellectual disabilities, but many other adults and more work needs to be done in order to make it more accessible and clearer.

In terms of physical health, interviews with some individuals also highlighted that physical health, including exercise and eating healthy, contributed to overall positive mental health. This perspective is supported within the literature (Mikkelsen et al. 2017) and provides support that some of the interviewees recognized that physical health contributes to positive mental health. Participants who highlighted physical health as a contributor recognized that mental health can be impacted by both negative physical health and positive physical health. For

example, one participant described in his interview that breaking one's leg would be painful but would also create fear for the future (alluding to trauma).

Unsure and relevant literature. As described in Chapter four, some participants also expressed that they were unsure about what positive mental health was. Throughout the interviews a number of participants checked in with the researcher to ask if their answer was correct or not. When participants asked such questions, the researcher explained to the participants that there was not a “right answer” and that the purpose of the conversation was to learn about what they thought in attempt to not influence their responses. In some cases, when asked about positive mental health, some participants expressed that they did not know. This indicates that individuals with intellectual disabilities sometimes had difficulty with the concept of positive mental health, either understanding what it meant or how to articulate it.

As discussed in the physical health section, one of the contributing factors for this uncertainty may have been the abstract nature of the concept of positive mental health. Individuals with intellectual disabilities may have difficulty with such topics. This is also consistent with previous research by Robinson and colleagues (2016) who conducted a study where adults with intellectual disabilities were interviewed about their subjective experiences related to living with psychotic symptoms. One of the areas highlighted by researchers when participants were interviewed was that they had limited knowledge about their diagnostic label, which impacted their support seeking behaviour. Researchers in this study suggested that one of the ways to support individuals with intellectual disabilities who have mental health difficulties is to provide them with psycho-education. In addition, Crowley, Rose, Smith, Hobster, and Ansell (2008) conducted a study where psycho-education was provided to individuals with intellectual disabilities that also had bipolar disorder or schizophrenia, and noted that psycho-

education appeared to be a positive experience for individuals who participated. The researchers noted that providing psycho-education improved some participants' self-esteem, was a means of empowerment for some, and supported individuals in help-seeking behaviour.

Positive qualities and relevant literature. Positive qualities were also discussed as being related to positive mental health. Some of the individuals interviewed throughout the research process identified positive actions as a part of positive mental health, which is consistent with the Public Health Agency of Canada's (2014) definition of positive mental health.

The capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice, interconnections and personal dignity (p. 3).

This definition highlights that enjoying life and the ability to face challenges is part of positive mental health. Some participants explained that part of positive mental health involved feeling emotions such as happiness. One participant explained:

I think that being happy contributes to being mentally healthy because if you're not happy people might think there's something wrong with you and ask you what's wrong. And maybe there are other thoughts going on in your head that you can't really get out of your head of a bad experience or something.

Another shared that people with positive mental health are "happy and cheerful." Such insights are important to note as some participants' descriptions aligned with the overarching definition, suggesting they understand part of positive mental health. However, the researcher noted that when participants were asked how they could achieve happiness, they appeared to have more

difficulty articulating an answer. The majority of participants highlighted that spending time with loved ones and participating in activities they enjoyed (e.g. sports) helped them to feel happy.

Another subcategory of positive actions was the idea of coping skills, which also aligns with the Public Health's Agency of Canada's definition of positive mental health – "to deal with the challenges we face". Some participants recognized that positive mental health included a component of overcoming obstacles. This is important also, as it highlights that some individuals recognize the importance of coping skills when discussing positive mental health. When participants were asked how they coped, they highlighted that thinking about good things and being in the moment were ways to improve positive mental health. The idea that participants were able to provide this information suggests that some individuals with intellectual disabilities can identify key elements of positive mental health that align with the current definition held in Canada.

Another area highlighted by participants as a component of positive mental health, was helping others. This is consistent with past research which has demonstrated a positive relationship between prosocial behaviour and the ability to cope with stress. One study explored how engaging in prosocial behaviour impacted participant's level of stress. Specifically, 77 participants were involved in the study and researchers concluded that prosocial behaviour reduced the impact of stress (Raposa, E. B., Laws, H. B., & Ansell, E. B., 2016). This is also consistent with a study in which individuals with intellectual disabilities who were involved in the community in a volunteering capacity were interviewed. They reported that volunteering was fulfilling, it provided meaningful activity, and an opportunity to be engaged in the community (Balandin, et. al., 2006). Participants described helping other people as source of happiness and meaning in their lives. For example, one participant said that it made her happy to bake cakes for

other people, in particular on their birthday.

The literature reviewed revealed that the majority of studies related to helping and individuals with intellectual disabilities were in the one-directional relationship (helping others with intellectual disabilities). However, there was less research about the benefits that helping others can have for those with an intellectual disability. This study provides first-hand information that individuals with intellectual disabilities recognize the importance of helping others for their happiness and as a definition of positive mental health.

Mental illness and relevant literature. The last category that participants mentioned when providing the definition of positive mental health involved mental illness, including both the presence of a mental illness or the absence of it. Some participants appeared to understand positive mental health as related to mental health issues. When one individual was asked to describe mental health, he described the idea of suicide. On the other hand, some participants explained that positive mental health involved the absence of mental illness.

The former description that emerged from the data involved positive mental health being described as related to mental illness. This is important to note, because just as in the “unsure” section, this section provides insight into the idea that there was confusion about what positive mental health was. It is the researcher’s opinion that given the abstract nature of the concept of positive mental health, participants may have described positive mental health based on what they know about it (for example, they may have known that it is related to suicide), however lacked a deeper understanding of it. This highlights the need for psycho-education about mental health in this population. This individual’s understanding of positive mental health is in contrast to the Public Health Agency of Canada’s definition.

Mental illness was also discussed as something that a person overcomes or does not have. One individual explained that overall positive mental health was the absence of mental illness, while the other described positive mental health as the ability to overcome difficulties with mental health. In terms of overcoming potential mental health difficulties, this understanding is consistent with the literature – that positive mental health involves overcoming obstacles. Of note, when this participant was asked how he would overcome mental health challenges, he appeared to have difficulty identifying strategies. Another participant shared that positive mental health meant that you did not have any mental health issues. Research does not support this view. Hubka and Lakaski along with other researchers have argued that mental health should include not only the absence of mental health conditions, but also the presence of positive views (2013).

Implications for Practice

As discussed in previous chapters, individuals with intellectual disabilities are at a greater risk of developing mental health disorders compared to those without an intellectual disability (Chen et al., 2006; Cooper et al., 2007; Razza et al. 2014; Reid et al., 2011). Of particular concern are young adults, as the transition out of high school can create anxiety for this population (Kaehne, 2011; Scior and Grierson, 2004). Given that little research has been done that highlights how individuals conceptualize positive mental health, this study is especially pertinent because it illuminates the need to provide instruction about mental health to such individuals. As discussed in Chapters one and two, people with intellectual disabilities are at a higher risk of developing mental health issues (Chen et al., 2006; Cooper et al., 2007; Razza et al. 2014; Reid et al., 2011), and this is especially true of young adults with intellectual disabilities (Kaehne, 2011; Scior and Grierson, 2004). In addition, there is evidence to suggest that understanding mental health (mental health literacy) contributes to positive mental health,

increases help seeking behaviour, and reduces stigma (Gulliver, Griffiths, & Christensen 2010). The current study highlighted that some individuals with intellectual disabilities struggle to understand the concept of mental health. It is therefore, crucial that individuals with intellectual disabilities are provided opportunities to learn about mental health at the level in which they can understand.

While there is research supporting prevalence rates of mental health issues in this population, little is known about the subjective experience and understanding that those with intellectual disabilities have around the idea of mental health. Within the literature there is support for the idea of mental health literacy, and the idea of understanding mental health, including positive mental health, as a protective factor against the development of mental health issues (Kutcher, Wei, & Coniglio 2016; Gulliver, Griffiths, & Christensen 2010). However, there is also little to no research around how individuals with intellectual disabilities understand mental health literacy despite its importance for this population

In this study, important insights for mental health professionals is provided, as it is one of the first of its kind to directly explore how those with intellectual disabilities conceptualize mental health. Overall, this research provides a great deal of support for the continued need for research in this area, particularly exploring evidence-based methods for providing psycho-education about mental health to persons with intellectual disabilities. Some important categories were highlighted which made it clear that within this population there are not only some great insights about positive mental health, but also a great deal of confusion and uncertainty. Many participants in the study expressed that they did not know what positive mental health was, or described it as being related to physical health. Others believed positive mental health was the presence of mental illness. These findings indicate that more work needs to be done to establish

methods for training such populations about positive mental health, as the research is clear, that understanding mental health literacy, can act as a protective factor. On the other hand, this study also suggests that there are some individuals within this demographic that describe mental health as the overcoming of mental health difficulties, and positive qualities (happiness, coping skills and helping others).

Throughout the study, careful attention was paid to capturing the views and experiences of this population. Qualitative interviews, follow-up conversations and the opportunity to communicate through pictures were all strategies the researcher used to provide methods to communicate with participants about this complex topic. However, the researcher noted throughout the process that this topic was often confusing for participants and they expressed they didn't know how to answer the question or presented conflicting definitions of positive mental health depending on the question. Additionally, based on the knowledge that the researcher had with the participant recruits, she was privy to the fact that they have had exposure to lessons on mental health in the past. All of this considered, this study highlights the need to further research that provides insights into how best to communicate a complex and abstract idea such as mental health with this population. It is also important to realize that while participants were provided lessons about mental health, it is not always best to assume they fully understand what is being taught.

Implications for School Psychologists

This study also provides valuable information for school psychologists. School psychologists have a unique role where they are often working with a diverse range of students, some of whom have intellectual disabilities. This study highlights the importance of providing psycho-education to individuals with intellectual disabilities. It also illuminates the difficulty that

this population may have understanding mental health, which indicates that school psychologists may need to be creative when providing psycho-education around mental health. Intervention and psycho-education around strategies to support the developmental of positive mental health in the school system is crucial to increase awareness and understanding. In addition, given the susceptibility to mental health issues and some of the challenges around understanding mental health, school psychologists can play a crucial role in educating others (students and school staff) to be aware and sensitive to this issue.

School psychologists also conduct psycho-educational assessments within the school system. Understanding how individuals with intellectual disabilities understand mental health is an important consideration when conducting a psycho-educational assessment because their understanding may impact their responses. For example, if a school psychologist asks about a student's experiences related to anxiety, the student may have trouble understanding what this is. Therefore, school psychologists must be sensitive and use language that is at the level of each individual to accurately discuss such issues. Additionally, given that individuals with intellectual disabilities are susceptible to developing mental health issues, school psychologists must be diligent with the implementation of prevention services for this population.

Limitations of the Current Study

While this study provided readers with many insights around how individuals with intellectual disabilities conceptualize positive mental health, it also had some limitations. Given the nature of qualitative research, the researcher is considered a data source which can introduce human error. Given the researchers previous relationship with some participants, additional error may have been introduced due to the researcher's bias or expectations of certain participants. In order to address this concern, methods were employed to ensure rigour which included member

checks, triangulation (using a researcher journal), and working with another researcher to ensure validity. Not only that, but as Sin (2010) recommends, the researcher demonstrated a commitment to reflexivity throughout the research process. The researcher identified possible biases that may exist and systematically questioned such biases during research.

Another limitation within this research study is the generalizability of current findings. While this study provides important information about the particular sample of participants interviewed, it does not however, provide findings that can be generalized to the greater population. While there is not set minimum number of participants, phenomenographic samples ideally consist of at least 15-20 participants. This study only included eight participants. One of the reasons for this was that a number of individuals approached at the independent living centre did not want to participate in the study. After consultation with the supervisory committee it was decided that given the setting features, recruiting at a second site and combining data would likely introduce additional limitations. In the future, a similar study should be conducted with more participants to more closely align with the phenomenographic method considerations for sample size. It also possible, that given the researchers previous relationship with study participants, the results of the study may be biased. However, careful attention was paid to this potential throughout the research project, including conversing with program staff about the role of a researcher, encouraging open communication, peer debriefing, consultation with the supervisor, and keeping a reflexive journal to help reduce potential bias.

Another potential limitation in the current study is the lack of female participants who were interviewed. The current study was made up of 8 males and 1 female. While recruiting participants, the researcher noted that the females in the independent living centre appeared hesitant to participate (with only one agreeing to be a part of the study). While it is difficult to

know the precise reason for this hesitation, it may suggest that female participants were experiencing differences related to mental health experiences, which made them less inclined to talk about it with the researcher. Had there been more females interviewed in the study, results may have differed.

Strengths of the Present Study

While this study had a few limitations, results of this project contribute to literature by providing first-hand accounts of how individuals with intellectual disabilities understand positive mental health. In the past, much research has focused on the prevalence rates of mental health issues within this population, without focusing on the views of individuals themselves (Kitchin, 2000). This study provides a stepping stone for further research to explore how positive mental health, as well as other components of mental health is viewed within this population.

Directions for Future Research

As highlighted throughout the discussion, one of the primary areas for further research involves exploring developmentally appropriate approaches to psycho-education about mental health issues. This study highlights that while there is some understanding about positive mental health, there is also a lot of uncertainty and confusion. It is imperative that curriculum be designed that targets this population and provides developmentally appropriate information and strategies to promote positive mental health. Such curriculums should also be tested using a randomized control design in order to evaluate their efficacy.

Overall, there is limited research in the field that directly hears from the voices of those with intellectual disabilities, therefore, it is imperative that future research continue to focus on this. Given the limitations of this research, it may also be beneficial to explore alternative approaches to conducting research with this population. The researcher used strategies such as

using simple language and providing an opportunity to draw during the study. However, in this study, conversations around drawings were used as data, rather than the drawings themselves. In the future, it may be useful to analyze the drawings themselves in order to gain more insight into how people with intellectual disabilities understand positive mental health and to gain a better understanding of the impact of using techniques such as drawings to explore this topic. It may be useful to explore other approaches, such as photovoice. Photovoice is a methodology that may be beneficial in hearing from the voices of those with intellectual disabilities by asking them to take photos about a topic.

Finally, large scale studies that provide more insight about mental health literacy for those with intellectual disabilities would be beneficial. Larger sample, quantitative studies would provide a great breadth of knowledge about how this population understands mental health issues. Large scale studies that explore how individuals understand mental health literacy would be informative and impactful when designing policy for this population.

Summary

Overall, this study provides insights into how individuals with intellectual disabilities conceptualize positive mental health. Many of the current results are consistent with previous literature, which suggests this is an abstract concept that can be difficult to conceptualize. When considered generally, this study provides support for the need for more research about how mental health is viewed within this population, and ways to provide psycho-education for this population that is effective.

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Appendix A

Initial Interview Protocol

The interview will be set up in a private space where the participant and researcher can have an uninterrupted conversation. Before beginning the interview, the researcher will spend some time talking with the participant about their day and what to expect during the interview. Additionally, they will go over the consent process in detail and answer any question that need to be addressed. They will explain to the participant that if they feel uncomfortable or want to stop the interview at any time they can.

1. Tell me about your understanding of mental health?

****Note, I will alter the questions below to integrate the participant's definition of mental health that they provide.**

2. What do you think it means when a person has positive mental health (or is mentally healthy)?
3. Describe someone who you think is mentally healthy?
4. Why do you think they are mentally healthy?
5. Tell me about an experience where you had positive/good mental health?
 - a. How did you feel in that situation?
 - b. Do you think others could tell you has positive mental health?
 - c. If so, how?
 - d. What factors do you think helped you to feel like you had positive mental health?
6. What does it mean when someone is mentally unhealthy?
7. What is an example of being mentally unhealthy?
8. What would it look like?

Appendix B

Before beginning the drawing portion of the interview the researcher will check in with the participant and ask how they are doing. They will ask if the participants would like to take a break. The researcher will introduce this section by telling participants they will do something a little bit different that will involve drawing and talking. The researcher will emphasize that drawing is another way to learn about how participants view positive mental health, and that the drawings are not being evaluated.

1. Draw a picture of someone you think has positive mental health.
 - a. The person can be real or made up. After you draw it, I will ask you to tell me about the drawing and why you choose to draw to the person, and well as elements about what you drew.
2. Draw a picture something you think helps you to feel good/have positive mental health.
 - a. Why did you choose to draw this?
 - b. What about it makes you feel good?
 - c. What does it feel like to feel good?

Appendix C

Clarification about definition of mental health (Physical health vs. mental health, happiness vs. positive mental health, mental health vs. mental health issues)

- What is mental health?
- What is the difference between being happy and being mentally healthy?
- What is the difference between a mental health issue and mental health?
- Tell me about how mental health is different from physical health.

Factors that influence mental health (Spending time with people and helping others as a source for mental health)

- What people in your life make you feel good? What about them makes you feel good?
- How do you feel when you help other people?

Past experiences that contribute to knowledge

- What have you learned about mental health? Where did you learn this information?

Appendix D

Background Information

The following information will be gathered via interview with the participant at the beginning of the first interview session after consent is obtained. Its purpose is to better understand a bit about the background of the participants.

What is your age? _____

Where do you live? (e.g. home with parents, in a group home, in an apartment with a roommate, etc.) _____

When did you start attending GROW? _____

Are you attending school or work training? _____ Yes _____ No

If yes, tell me about your school or work training (e.g. full time student, part time student, community college, vocational training, etc)

Are you currently employed (working and getting paid)? _____ Yes _____ No

If yes, tell me about your work, how often do you work and what type of job do you have (e.g. full time, part-time, grocery checker, retail, etc.)

Appendix E

Exploring Perceptions of Positive Mental Health in Young Adults with Intellectual Disabilities: Participant Consent Long Version

Note: Given the developmental level of the participant a shorter version of this will accompany the consent. The consent will be reviewed in person, verbally, at a level appropriate for the participant.

Principal Investigator:

Laurie Ford, Ph.D.

Department of Educational & Counselling Psychology & Special Education,

Phone: XXX-XXX-XXX

Email: xxxxx@xxxx.xx

Student Co-Investigator:

Darcie-Anne Bailey

Department of Educational & Counselling Psychology & Special Education

Phone: XXX-XXX-XXX

Email: xxxxx@xxxx.xx

Why are we doing this?

Darcie-Anne Bailey and Dr. Laurie Ford have invited you to participate in this study because we want to learn about how young adults with special learning needs understand the concept of positive mental health. We will explore this by talking with you about what you know about mental health and positive mental health. The information we learn will be used for the thesis of one of the researchers, Ms. Bailey.

What will happen if you take part?

- Ms. Bailey will talk with you (an interview) to learn about your experience with and what you know about positive mental health.
- We will also do a drawing activity with you to help us learn about what you know about positive mental health.
- We will also ask you a few questions about your background.
- We will talk with you at GROW independent living centre or another place that is quiet if that is better for you.
- We will talk with you for about 30 to 60 minutes.
- The interviews will be audio-recorded and notes will be taken while we talk. If you do not want to be audio-recorded then you should not participate.
 - Please indicate if you agree to be audio recorded:
 - i. Yes
 - ii. No

After the interview:

- After the interview, Ms. Bailey will transcribe (write it out on paper) the audio recording.
- After they have been transcribed the interview Ms. Bailey would like to meet with you a second time to review our talk.

- The second meeting will take about 30 minutes. It is your choice. If you do not want to do a second meeting to talk about the transcript that is ok.

Additional Information

- The research team does not believe it is a risk to take part in our study. However, if there is anytime you do not feel comfortable, we can stop our talk. You can stop participating in the study at any point. If you withdraw from the study, the audio recording, notes, and drawings will be destroyed.
- If you have any questions you can talk with us anytime. We can talk with you in person or you can call us at the phone numbers at the top of this letter. You can also email us any questions. Our emails are written at the top of this letter.
- We will not use your name on anything we write about the study. **No individual information will be reported and no participant will be identified by name**
- We will share the things we learn from the study in the thesis for Ms. Bailey, presentations, and other written papers. However, we will never use your name or the name of the centre.
- All of the information from our talk and our study will be kept locked and safe. Only Dr. Ford and Ms. Bailey can get the information.
- All paper data files will be stored in a locked filing cabinet in the lab and electronic and digital files in password protected/encrypted files on the UBC campus for a minimum of 5 years after the completion of the study and presentation or publication of results. At the end of the 5 year period, if there is no need for the data, paper copies may be shredded and electronic and digital files will be deleted.
- If you have any concerns or complaints about your rights as a person taking part in this study and/or your experiences while taking part in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics, at 604-822-8598 or if long distance, email RSIL@ors.ubc.ca or call toll free 1-877-822-8598.
- If you want to know about what we learn we will share a copy of the results with you in person or in a short written paper.
 - Please indicate if you like a copy of the results by circling a response:
 - i. Yes
 - ii. No

Consent to Take Part in Our Study

If you sign your name below it means you consent (want) to take part in this study. When you sign below is also means that you have received a copy of this consent form for yourself.

Your Name (please print):

Your Name (sign):

Today's Date: _____

Appendix F

Positive Mental Health and Young Adults CONSENT: BRIEF VERSION

(This will be reviewed verbally with the participant, with this paper copy in front of them)

I, Name:

Purpose of the study:

To learn about how you understand and define positive mental health.

What will happen if I take part in the study?

- You will talk with us about your ideas and views about positive mental health. You will also be asked to tell us a little bit about your background. We will also ask you to do some drawing during our talk. Our talk will take about 30 to 60 minutes.
- We will talk with you at GROW or another quiet place.
- We will audio-record our talk and write it up when we are done.

Do you have any questions? Yes _____ No _____

Do you agree to this study? Yes _____ No _____

What will happen after our interview?

- We will transcribe (write up) the interview.
- We will see if you would like to talk with us again to review what you said during our talk.

Do you have any questions? Yes _____ No _____

Do you agree to this study? Yes _____ No _____

Are there any things for me to worry about (risks for me) if I take part in the talk?

- We do not believe there is any risk if you take part in the study. If you do not feel comfortable and want to stop, you may stop at any time.
- All the information you tell us will be kept private, and your name will not be on anything and we will not share it with anyone not part of our team.

Do you have any questions? Yes _____ No _____

Do you agree to this study? Yes _____ No _____

What else is important for me to know?

- If you take part you agree for the information you share to be used in research and school projects (such as presentations). However, your name or the name of the centre will not be shared.
- If you have any concerns or complaints about your rights as a research participant and/or your experiences while taking part in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics, at 604-822-8598 or if long distance, email RSIL@ors.ubc.ca or call toll free 1-877-822-8598.
- If you want to know about what we learn we will share a copy of the results with you in person or in a short written paper.
 - Please indicate if you like a copy of the results by circling a response:
 - Yes
 - No
 -

Do you have any questions? Yes _____ No _____

Do you agree to this study? Yes _____ No _____

YOUR CONSENT

Do you **understand** what taking part in this study means?

Yes _____ No _____

Do you have any questions?

Yes _____ No _____

If you want to take part in our study (**consent**) please sign below:

Please print your name: _____

Please sign your name: _____

Today's Date: _____