# Identity in Motion:

A Case Study on the Dance Experiences of a Dancer with an Intellectual Disability

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#### **Abstract**

Many individuals with intellectual disabilities (ID) experience significant challenges and are underserved in our society. Although some of these challenges are directly related to their disability, most of the difficulties that people with ID face are caused by negative social attitudes towards ID. The negative consequences of stigmatization towards people with ID create barriers to creating positive sense of self among members of this population. Studies indicate that leisure pursuits, such as recreational dance, can help cultivate well-being and enhance sense of self. This hermeneutic phenomenological case study provides new understanding to the phenomenon where dance, disability, and sense of self intersect. This case study explores the experiences of one individual with an ID who is involved with recreational dance and presents the ways that recreational dance impacts the sense of self of this individual. The results from this research reveal that recreational dance positively contributes to well-being. The experiences of this young dancer were addressed primarily in terms of his social connections, character strengths, and personal growth. In addition, dance has a positive impact on his sense of self as it enhances his self-confidence, provides him with positive feedback from others, and offers a context through which he can overcome barriers and challenge stigmatization. This case study provides insight on leisure-related concepts as well as offers implications to individuals with ID, integrated dance, and the therapeutic recreation profession.

Keywords: Intellectual disability, recreational dance, leisure, sense of self

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# **Chapter 1: Introduction**

As someone with experience supporting individuals with disabilities, and experience with and a passion for dance, I approach this research with a desire to learn more about the place where dance and people with disabilities intersect. During my experiences dancing with former clients, I grew curious about what these experiences meant for people with disabilities. I wanted to know how, if at all, dance impacted the way such individuals saw themselves. It is through this research opportunity, that I fed my curiosity and shed light on this valuable phenomenon.

This phenomenological case study explores the experiences of recreational dance for an individual with an intellectual disability (ID) and the impact of recreational dance on the sense of self of this individual. Several months ago, I met a young dancer with an ID, and it was during the months to follow that I had the privilege of getting a glimpse into this person's life, his family, and his community. I was able to gain a sense of who he is, how he uses dance as an integral part of his life, and how dance has helped shape the ways he sees himself.

According to Statistics Canada (2006), intellectual disability (ID) affects 0.7 percent of individuals living in Canada. Further awareness and understanding of ID could dramatically improve the lives of individuals with ID and their families (Battaglia et al., 2013). When compared to individuals without ID, research indicates that individuals with ID construct poorer sense of self (Datta, 2014), which is an important aspect of experiencing success and well-being (Broderick & Blewitt, 2006; Datta & Halder, 2012). Research reveals that having an ID can negatively impact the quality of one's sense of self (Datta, 2014). Studies show that leisure activities, such as dance, can improve sense of self among people with ID (Duerden, Taniguchi, & Widmer, 2012; Harmon, 2015). In this chapter, I will provide a description of my personal stance that I bring to this research. I will also introduce ID and briefly explain the impact of

stigmatization among individuals with ID. Next, I will present the term 'sense of self' and briefly discuss sense of self among people with ID and how leisure pursuits, such as dance, can impact sense of self among people with ID. Last, I will state the research questions that guided this study.

## **Personal Stance**

I carry with me my experiences, perceptions, and notions, which create lenses through which I view the world. Conducting research is no different; my experiences and ideas form biases and assumptions which I inevitably bring to my research. These personal perspectives have not only impacted my relationships with the research content and participants, but they also shed light on the reasons grounding my research interests. With that, the following is a short history about me and glimpse into my sense of self.

During the past 12 years, I have volunteered and worked with people with developmental disabilities in various capacities throughout Toronto and surrounding areas. During the past three years, I have been learning about and beginning to practice therapeutic recreation and gaining an understanding of how I can use this practice to help support people with disabilities and illnesses, and ultimately better people's lives.

During my first volunteer experience supporting children with physical and developmental disabilities, I felt a clear sense of belonging and purpose. Growing up in a family and community of professionally high achievers, while battling learning and anxiety disorders, I have often felt "disabled" in my own way. I believe my diagnoses help me identify with many of the struggles experienced by many of the individuals with whom I have had the privilege to connect. As I gained more work and volunteer experiences with people with a variety of abilities and learned more about social attitudes associated with such populations, my focus and work

with people with disabilities has increased, and my outlook on disability has evolved. I have and will continue to help normalize disability through promoting a strength-based perspective, awareness, and genuine community inclusion for people with disabilities.

My experiences with dance have been filled with joy, pain, tension, release, passion, and self-expression. I have always loved to dance and perform. When I was seven, I began to take community-based recreational dance classes on a weekly basis for six years, after which I participated in high school and university productions. I often wonder how I might have changed if I had taken competitive dance, as opposed to recreational dance. Perhaps it would have helped me become a better dancer; perhaps it would have made me less able to feel the joy and sense of freedom dance brings me.

Throughout my youth, I would occasionally fantasize about becoming a dancer, but always thought that it was too far of a reach given my limited dance experience. As this fear around not trying to 'live my dream' grew, with hardly any technical training behind me, I mostly danced (and partly talked) my way into the Bachelor of Fine Arts program in Dance from York University. It was here, where I received the training I wanted and became the best dancer I could be. Ultimately, I learned that the dance profession was not the field to directly shape my future career.

Having a learning disorder can often make it challenging for me to remember choreography, and thus my passion with dance revolves around improvisation. Over the past 10 years, I have helped organize and lead private, corporate, and community dance-based events for a few different Canadian entertainment companies leading improvised dance events. I continue to create and implement dance programs with my work with people with disabilities.

Like others, dance has informed my sense of self. Dance is an outlet for me to express myself. It allows me to expel frustration, process emotion, and celebrate my body and life.

Dance provides me with a sense of comfort, freedom, optimism, and has allowed me to see things in new ways. Perhaps it is the special role that dance plays in my own life that has driven me to attempt to understand its role in the lives of others, specifically those with ID.

## **Intellectual Disability**

Under the umbrella of developmental disabilities (American Association on Intellectual and Developmental Disabilities, 2010), ID is a broad diagnosis which manifests a wide variety of characteristics and severities (Battaglia et al., 2013). According to the American Association on Intellectual and Developmental Disabilities (AAIDD), ID, formerly known as mental retardation, refers to "a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills" (AAIDD, 2010, para. 1). Furthermore, the AAIDD states that intellectual disabilities originate before the age of 18. The AAIDD measures intellectual functioning, also known as intelligence, using an intelligence quotient (IQ) test and states that an IQ test score as high as 75 indicates a limitation in intellectual functioning. The same association measures adaptive behavior, including conceptual, social, and practical skills, using standardized tests (AAIDD, 2010). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the severities of ID are categorized into mild, moderate, severe, and profound (American Psychiatric Association [APA], 2013). Many individuals with ID experience significant challenges. Not only are many of these challenges disability-related, but the difficulties that people with ID most often face are challenges that are socially created, such as stigmatization, referred to as stigma for short.

## **Stigmatization**

As a result of negative social attitudes towards ID, individuals with ID are often underserved in our society. Despite the various negative consequences of having a disability, the most disabling experiences for people with ID are caused by stigma (World Health Organization [WHO], 2001). Stigma is an ongoing problem and can result in social exclusion, limited choices and rights, and abuse (Ditchman, Kosyluk, Lee, & Jones, 2016). For example, individuals with ID experience significantly higher rates of poverty and isolation, lower employment rates, and are at greater risk of experiencing harassment, violence, and abuse of many kinds than individuals without ID. Structural stigma has also lead to exclusion within the education system, providing individuals with ID segregated education, often of lower quality (Ditchman et al., 2016). Moreover, individuals with ID receive inadequate routine healthcare, limited opportunity to develop intimate relationships, and reduced access to sexual health and safety education. Last, individuals with ID experience lower levels of community engagement, fewer social relationships, and less participation in leisure pursuits than those without ID (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). The negative consequences of stigmatization towards people with ID can create barriers to creating positive sense of self among members of this population.

## Sense of Self

There are several benefits of having a positive sense of self. The quality of one's sense of self can often dictate or explain future behavior (Shavelson et al., 1976). Building a more positive sense of self is cyclically beneficial as it can offer individuals greater self-determination, tools to cope better with stress and adversities (Dua, 1993), and strengthen a sense of self-actualization (Green, 1984). Furthermore, sense of self is an important part of social and

psychological development as it can impact well-being (Broderick & Blewitt, 2006) and can cultivate achievements and optimism in different domains of life (Datta & Halder, 2012).

Studies show that improving the quality of sense of self among individuals is a significant goal among the general population (Datta, 2014), however it is exceptionally important for individuals with disabilities who experience barriers that negatively impact their sense of self. People with ID are generally prone to developing poor sense of self due to various challenges, such as barriers to academic and social opportunities and achievements, stigmatization and discrimination, unemployment and underemployment (Elbaum & Sharon, 2001), inadequacy and inferiority (Beaty, 1991), and low expectations from others (Blomquist et al., 1998).

Similar to people without ID, studies reveal that developing a positive sense of self contributes to the development and overall well-being of people with ID. Additionally, creating positive sense of self among individuals with ID is correlated with higher levels of psychosocial adjustment and functioning (Levy-Shiff, Kadem, & Sevilla, 1990), as well as higher perceived overall quality of life (Emerson, 1985). Most of the literature reveals that individuals with ID construct and express a sense of self (Harter, 1999), however the quality of these sense of selves is inconsistent.

While some studies suggest that individuals with ID appear to have more positive sense of self than individuals without ID (Duvdevany, 2002), many findings indicate that people with ID have more negative sense of self when compared to people without ID (Datta, 2014). Researchers explore this discrepancy, and many argue that stigmatization and the desire 'to be seen as ordinary' can impact the way people with ID construct or express their sense of self (Beart, Hardy, & Buchan, 2005; Dorozenko, Roberts, & Bishop, 2015). The literature presents several barriers that individuals with ID may experience when forming positive sense of self,

which are related to social relationships, stigma, employment, negative prognoses, and social services. There are many ways to develop more positive sense of self. One of these methods is through cultivating a satisfying leisure lifestyle.

## Leisure

One of the ways that individuals can impact the way they view themselves is through leisure engagement. Hood and Carruthers (2013) define leisure experiences as:

Engagements that are (1) pleasant in anticipation, experience, or recollection; (2) pursued for the intrinsic rewards inherent in the activity; (3) perceived as chosen in relative freedom; (4) expressive of essential aspects of the self; and (5) experienced in contrast to whatever is going on before or after and thus often involves a shift in perception and/or engagement. (p. 122)

According to Kleiber (1999), leisure is a prime context for youth to develop their personal identities. There is considerable attention paid to individuals with illnesses and disabilities within the research on leisure and sense of self.

Personal development. Studies reveal that leisure can provide individuals with opportunities that can enhance their personal development, which supports personal sense of self. For instance, leisure can help people gain new skills, increase self-confidence, and a sense of pride and accomplishment, which support positive sense of self development (Duerden et al., 2012; Erikson, 1963; Hamachek, 1988; Stumbo & Peterson, 2009). Furthermore, new experiences, positive emotions, and autonomy are beneficial for building a positive sense of self, which are all aspects that can be gained through leisure participation (Erikson, 1963; Manell & Kleiber, 1997; Stumbo & Peterson, 2009). Moreover, leisure allows people to establish personal interests and offers opportunities for self-reflection, solace (Boyce & Fleming-Castaldy, 2012;

Kleiber 1999), and self-expression (Erikson, 1969), which can benefit personal sense of self (Stumbo & Peterson, 2009).

Connection. Developing a sense of self relies heavily upon social interaction as it is partly the feedback from others that contributes to building a sense of self (Erikson, 1963; Shevalson et al., 1976). Social connections are often achieved through leisure experiences, which can directly inform how individuals view themselves (Kleiber, 1999). For instance, social leisure experiences can provide individuals with a sense of belonging and identity, which can directly inform sense of self (Kleiber, 1999). In addition, the literature claims that leisure develops and fosters social support networks, social identities (Hood & Carruthers, 2013; Stumbo & Peterson, 2009), social engagement, and community involvement (Caldwell, 2005), which are also important for developing a positive sense of self (Erikson, 1963). Furthermore, according to Erikson (1963), building a social network is important for constructing a positive sense of self. Moreover, leisure can provide individuals with social relationships, which also may contribute to a positive sense of self (Erikson, 1963; Stumbo & Peterson, 2009).

For many individuals with disabilities and illnesses, social acceptance and freedom from negative stereotypes and stigmatization support positive sense of self development. Research presents that social acceptance and reduced stigmatization can be gained from leisure pursuits (Lundberg, Taniguchi, McCormick, & Tibbs, 2011). For instance, the literature provides many examples of leisure promoting a sense of normalcy towards illness and disability and often bridges the gap between individuals with and without illnesses and disabilities (Lundberg et al., 2011). There are endless types of leisure activities. The leisure modality of dance will help shape this study.

#### Dance

According to Beardsley (1982), dance can be defined as "a motion, or sequence of motions, [that] does not generate practical actions, and is intended to give pleasure through perception of rhythmic order" (p. 35). For some, dance embraces what it means to live in the world and to express our experiences of life (Block & Kissell, 2001). Dance scholars argue that people are natural movers, which is evident in toddlers organically bouncing and shaking to music and nursery rhymes. Furthermore, people can dance regardless of age or abilities (Oliver & Hearn, 2008). Today, people dance in vastly diverse settings with various intentions. Along with social dancing, including that which is enjoyed at celebrations, dance can also be taught recreationally or competitively through educational curricula, private dance studios, or other community settings (Oliver & Hearn, 2008). Furthermore, there are countless dance styles in North America; some are more widespread and popular, such as ballet, jazz, hip hop, and tap, and others are more culturally specific, such as Tinikling from the Philippines and Atilogwu from Nigeria.

Dance can be an ideal physical leisure activity for individuals with ID as it provides opportunities for non-verbal self-expression, which may be more accessible than conventional ways of self-expression, such as verbal expression. Furthermore, although many dance genres have rules related to technique, it can offer people opportunities for creativity. For people with ID, fulfilling societal expectations can cause feelings of inadequacy and inferiority (Beaty, 1991). Improvisational dance, like other artforms, can offer opportunities to create art and communicate to others without needing to meet specific outcomes. In other words, dance offers people a blank-slate with which to tell stories and express emotion.

There are various benefits of dance pertaining to sense of self development. For instance, dance can enhance emotional well-being in many ways, including building confidence (Oliver & Hearn, 2008), relieving stress, and cultivating excitement (Stinson, 1997). Additionally, the psychological benefits of dance include developing a sense of self and connecting with individuals' true or inner selves, as well as providing people with a sense of freedom, transcendence, and 'being in the moment' (Stinson, 1997).

Despite the progress among attitudes and treatment of people with disabilities, our North American society, as progressive as it may seem, is generally designed for people without disabilities. This is evident among the disparities within education and employment, community and leisure spaces, and legal and political arenas. We can even see this within the dance community. The prototype dancer is typically tall (but not too tall), thin (but not thin enough), and abled-bodied. However, the dance community is beginning to broaden their definition of a dancer. I hope that we can work towards showcasing more dancers with disabilities and create more dance opportunities that include people with disabilities, as opposed to offering dance opportunities specifically geared toward people with disabilities, which continues to separate dancers with disabilities from dancers without disabilities. Not only are accessible dance opportunities limited in Ontario, but the accessible dance opportunities that do exist are targeted for and are generally participated in by people with disabilities exclusively. I hope that dance arenas become more inclusive and accessible, both physically and attitudinally, to allow for "inclusive" dance opportunities to truly be inclusive and involve people with all abilities. It is with this hope that I came to this research in efforts to give voice to members of the dance community who are often marginalized or go unseen entirely.

Dance and individuals with ID. Dance, including recreational dance, can offer people with ID an opportunity for developing sense of self, social acceptance, and a sense of belonging. Studies show that dance can also contribute to self-acceptance and self-love among people with ID (Block & Johnson, 2011; De Tord & Brauninger, 2015; Harmon, 2015). For example, according to Becker and Drusing (2010), community-based dance programs provide people with ID opportunities for social experiences, which the literature argues to be important for developing positive sense of self (Kleiber, 1999). In addition, studies indicate that communitybased dance experiences can also promote peer acceptance (Zitomer, 2016) and a sense of social responsibility among people with ID (Block & Johnson, 2011), which contributes to positive sense of self (Kleiber & Kirshnit, 1991; Mannell & Kleiber, 1997). Furthermore, the creativity and freedom often experienced from dance can provide people with ID with opportunities to cultivate self-expression (Block & Johnson, 2011), which Erikson (1969) stated is significant for developing a positive sense of self. Lastly, Band et al. (2011) indicated that dance can enhance the self-esteem and self-efficacy among people with ID, which are major aspects of a positive sense of self (Erikson, 1963).

# **Research Questions**

Developing a positive sense of self improves perceived quality of life. In addition, research indicates that individuals with ID often develop relatively poor sense of self. Leisure may be one avenue through which sense of self can be enhanced. Finally, studies show that dance can have a positive impact on sense of self.

This case study sought to provide new understanding to the phenomenon where dance, disability, and sense of self come together. This research explores the experiences of one individual with an ID who is involved with recreational dance. In addition, I sought to

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understand the ways that recreational dance can impact the sense of self of one individual with an ID.

This study aims to answer the following primary research question and secondary research question: How might an individual with an intellectual disability describe his experience with community-based recreational dance? In what ways, if any, does recreational dance impact an individual with an intellectual disability as it relates to his sense of self?

## **Chapter 2: Literature Review**

Research indicates several ways that leisure activities, which include recreational dance, can enhance sense of self among people with ID. This chapter will outline the literature that supports the relationship between ID, sense of self, leisure, and dance. First, I will discuss sense of self among individuals with ID. Second, I will review the research on the impacts of leisure on sense of self. Third, I will explore the literature on leisure among individuals with ID. Fourth, I will introduce therapeutic recreation, a professional lens through which I will conduct this study. Fifth, I will outline the research findings on dance as it pertains to people with ID. Finally, I will present the literature on research participation from individuals with ID.

# **Intellectual Disability and Sense of Self**

The literature uses several terms to mean sense of self, including self-concept, identity, and self-image. For the purpose of this research study, I will use the term 'sense of self' to illustrate this construct. Similarly, there are several ways to define sense of self. This research will consider sense of self in terms of the narrative self. According to Vice (2003), "selfhood or identity is constituted by the narratives that we tell about ourselves" (p. 93). In other words, the ways in which we develop our sense of self are based on the individual narratives that we create to guide our perceptions. Vice (2003) continues to explain that narrative self acknowledges that people naturally view their experiences as an evolving story, with characters, often the individual as the protagonist, and lessons learned along the way. As a term within the social sciences and humanities, narrative "is a system of understanding that we use to construct and express meaning in our daily lives" (Guerrero, 2011, p. 89). This theory suggests that people impose a narrative structure to the world and their experiences of the world. In this way, narrative is the lens through which we experience our lives and understand ourselves. Narrative views suggest that people understand their lives in a chronological and linear narrative, which seeks to establish

patterns, unity, and closure (Vice, 2003). The narrative approach allows people to view the seemingly unrelated and even unpleasant life events as experiences that are parts of a whole journey (Ochs & Capps, 1996). In this way, the narratives that we share about our lives ascribe meaning, purpose, and connection to otherwise seemingly insignificant or isolated events. Schechtman (1996) states:

The sense of one's life as unfolding according to the logic of a narrative is not just an idea we have, it is an organizing principle of our lives. It is the lens through which we filter our experience and plan for actions, not as a way we think about ourselves in reflective hours. (p. 113)

According to Shavelson et al. (1976), sense of self is based on one's experience with and interpretations of one's environment as well as the attitudes of significant others. According to Popovici and Buica-Belciu (2013), sense of self is centred on self-esteem, self-efficacy, perceived competence, and level of abilities and acquired skills compared to peers and significant individuals.

Research suggests that there is a lack of consistent theoretical models to support the measurements and interpretations of one's sense of self. Shavelson et al. (1976) attribute this to the ambiguous and varying definition of sense of self and researchers continuing to develop specific tool to measure and interpret their specific approach to sense of self. However, one theoretical model that has gained wide acceptance is the hierarchal organization of sense of self created by Shavelson et al (1976). These researchers identified seven features of sense of self, which continue to frame the theory behind sense of self today. These features are: organized, multifaceted, hierarchal, stable, developmental, evaluative, and differentiable. From these features, Shavelson et al. (1976) developed a multifaceted hierarchal model of sense of self,

which proposes sense of self to be multidimensional. This model divides general sense of self into 'Academic Sense of Self' and 'Non-Academic Sense of Self'. The latter category is further divided into 'Social Sense of Self', which addresses peers and significant others, 'Emotional Sense of Self', which focuses on particular emotional states, and 'Physical Sense of Self', which considers physical ability and physical appearance (Shavelson et al., 1976). More current research provides empirical evidence which supports the multidimensionality of sense of self (Marsh, Barnes, & Hocevar, 1985). For example, Harter (1999) confirms that sense of self includes various unique domains, which can be assessed individually, such as academic competence, physical appearance, and social acceptance.

Although there is a lack of widely accepted tools that assess general sense of self, there are several tools that are used to measure and interpret the sense which involve self-estimates. Most of these instruments are questionnaires and typically based on their own definition of sense of self (Marsh, 1990). Examples of such instruments include "How I See Myself Scale" (Gordon, 1966), The Self-Description Questionnaire (Marsh, 1988), and The Sense of self and Identity Measure (Kauffman, Cundiff, & Crowell, 2014).

There are significant benefits of constructing a positive sense of self. The quality of one's sense of self can often predict or explain his or her behavior (Shavelson et al., 1976). Research suggests that individuals with a more positive sense of self are more likely to be self-determined, cope better with stress (Dua, 1993), and experience a stronger sense of self-actualization (Green, 1984). Sense of self is an important part of social and psychological development as it can impact the well-being and personalities of individuals (Broderick & Blewitt, 2006) and can cultivate achievements and optimism in many different life domains (Datta & Halder, 2012). Furthermore, Franken (1994) argues that sense of self allows people to explore various possible

ideas of themselves, which can motivate behavior. Studies show that improving the quality of sense of self of individuals is a significant goal among the general population (Datta, 2014); however, it is exceptionally important for individuals with disabilities, who experience barriers to constructing positive sense of self.

Enhancing sense of self is particularly important among people with ID, who often face challenges and experience adversities regularly (Craven, Marsh, & Burnett, 2003). Because research on the sense of self of individuals with ID is in the embryonic stages, there is a great need to further explore this topic (Palmer, 2003). Research on sense of self among individuals with ID presents conflicting arguments around the ability of people with ID to construct reliable and realistic sense of self. For example, research conducted in 1998 found that people with ID are capable of completing realistic assessments (Evans, 1998) across a plethora of domains (Harter, 1999). However, more recently, Zolkowska and Kaliszewska (2014) suggest that people with ID lack or have limited abilities that may impact their capabilities to construct a sense of self. Despite this discrepancy, individuals with ID maintain a self of self across a magnitude of domains (Harter, 1999).

In general, experts argue that developing a positive sense of self is important to the development and overall well-being of people with ID. For example, developing a positive sense of self is correlated with high levels of psychosocial adjustment and functioning (Levy-Shiff et al., 1990), as well as a sense of overall quality of life for people with ID (Emerson, 1985).

In the following section, I will present the factors and barriers that influence sense of self among people with ID followed by the quality of sense of self among people with ID. Lastly, I will explore the role of disability within sense of self.

# **Factors of Sense of Self Development**

There are several factors that can either negatively or positively inform the quality of the sense of self that individuals with ID form, which can be divided into the following categories: social relationships, employment, negative prognoses, social services, and stigmatization.

The first category of factors that can influence sense of self among individuals with ID is social relationships. Some research findings reveal that perceptions of parental support (Jones, 2012) and positive social relationships with partners, family, friends, peers, and co-workers are significant in creating sense of self (Ping-Ying Li, Sing-Fai Tam, & Wai-Kwong Man, 2006). Because developing positive relationships and appropriate and supportive connection with others is important for creating a positive sense of self among people with ID, creating a positive sense of self can be difficult for those without supportive relationships.

Moreover, the literature indicates that social attitudes and behaviors towards people with ID largely shape sense of self among this population (Duvdevany, 2002; Huck, Kemp, & Carter, 2010; Popovici & Buica-Belciu, 2013). For instance, a study that assessed the sense of self of students with Down syndrome across various schools, ages, and gender, found that the students who went to inclusive schools generally had a more positive sense of self than those in segregated schools (Begley, 1999). Furthermore, other studies described inclusive settings to be empowering for individuals with ID and help individuals to feel they are fulfilling general expectations (Coleman, 1983). In the same way, negative social attitudes, stigma, and segregation are major factors which influence the quality of sense of self that individuals with ID construct (Coleman, 1983). Negative social attitudes towards ID and its associated results, such as segregated and exclusive environments and opportunities, can cause major barriers to creating positive sense of self among people with ID.

The second category of factors that research describes as influential to the quality of sense of self formed among people with ID is employment. A study that explored sense of self among individuals with ID in Hong Kong discovered that employment improves sense of self as many participants expressed their satisfaction from work-related achievements, especially earning money (Ping-Ying Li et al., 2006). The unique social benefits that these employment opportunities provided was also addressed by the participants. Because employment dramatically improves the quality of sense of self among people with ID, the lack of employment opportunities accessible to people with ID is a major barrier to these individuals maintaining positive sense of self.

A third category relates to the way in which ID diagnoses are presented to individuals and their families. In a recent study that interviewed Australian adults with ID found that medical professionals often deliver ID prognoses in a tone of misfortune and hopelessness (Dorozenko et al., 2015). Some of the participants from this study internalized such outlooks by medical professionals and consequently viewed themselves as burdens to their families and tragedies, which negatively impacted their sense of self (Dorozenko et al., 2015).

An additional category of influential factors that the literature discusses is involvement of support services and institutions. Ironically, research indicates that services, such as support agencies for people with disabilities, can ultimately hinder the ability of its members to envision cultivating identities beyond being recipients of support (Midjo & Aune, 2016). Other findings reveal that the resistance of appearing as different from those without ID greatly dictates the way that such individuals see themselves (Dorozenko et al., 2015). Because of innate desires to be seen as ordinary, stigmatization can create barriers for people with ID to construct positive sense of self. The literature suggests that if there were more tolerant and realistic perceptions of people

with ID, members of this population would develop more positive and realistic images of themselves.

# **Quality of Sense of Self**

The literature suggests that the considerable challenges that people with ID encounter, such as barriers to academic and social opportunities and achievements, stigmatization and discrimination, and unemployment and underemployment (Elbaum & Sharon, 2001), negatively inform their sense of self. Adolescents with ID are especially susceptible to feeling inadequate and inferior (Beaty, 1991), which can negatively influence their sense of self (Datta, 2014). Moreover, Blomquist et al. (1998) claim that youth with ID experience significant challenges, such as low expectations from others, a lack of knowledge about career and educational opportunities, and poor self-advocacy skills, which can negatively influence sense of self. Lastly, research has compared the impact of segregated and integrated settings on sense of self, however the results are conflicting. Paterson, McKenzie, and Lindsay (2012) found that in segregated settings, individuals with ID often engage in social comparison with people without ID, which can cause individuals with ID to construct a poor sense of self. However other research reveals that perceptions of stigmatization among integrated environments can negatively impact sense of self among people with ID (Abraham et al., 2002). It is likely that further research in this area will help clarify and explain this discrepancy.

The literature also reveals contradictory findings on the quality of sense of self among individuals with ID. There are many studies which conclude that individuals with ID have more negative sense of self than people without ID (Garaigordobil & Perez, 2007). However, other findings suggest that individuals with ID have more positive sense of self than those of individuals without ID (Ping-Ying Li et al., 2006; Duvdevany, 2002).

## **Content of Sense of Self**

Although the literature presents conflicting findings in terms of the quality of sense of self among individuals with ID, the findings consistently reveal that the nature of the sense of self among individuals with ID is ordinary and similar to those of individuals without ID (Dorozenko et al., 2015; Midjo & Aune, 2016). Findings reveal that having an ID is generally not the focus, nor sometimes even mentioned, in the sense of self of individuals with ID (Kittelsaa, 2014).

The sense of self of people with ID that are explored in the literature are approached in various ways. For instance, a study in which 51 adolescents with developmental disabilities, including ID, were interviewed on their self-perceptions, 60 percent of the participants mentioned activities that they enjoyed, and almost half of the respondents described their physical characteristics (Jones, 2012). In the same study, other approaches to explaining their self-perceptions included personality characteristics, gender, and race, and 20 percent described their physical characteristics that they would like to change, which included their disability and associated stigmatization (Jones, 2012).

A similar study demonstrates that a common aspect of sense of self among individuals with ID is the importance of close relationships. Using photovoice and conversational interviewing, these individuals described their relationships, including intimate relationships, family, friends, and pets (Dorozenko et al., 2015). For instance, many participants photographed their boyfriend/girlfriend or husband/wife and discussed the many things these relationships provided them, including companionship and a sense of belonging. This was evident during an interview with a couple who both have ID. They explained, "I decided to take a photo of my girlfriend...She's sweet, she's nice to me and that's what I want in my life" (Dorozenko et al.,

2015, p. 1355). During their interview, the couple also discussed plans to move into their own home and potentially start a family in the future (Dorozenko et al., 2015). Along with relationships, national identity and a sense of community were also common aspects among the sense of self of the participants in this study. For example, church was described by some of the participants as an important way to connect with community and make friends. Moreover, several of the participants had active roles in their churches, such as an alter server, which one proudly described as a formal and respected role (Dorozenko et al., 2015). In addition to relationships and community, employment played a central role in the sense of self of the participants of this study. Many of the photographs and discussions were related to their place of work, which was often open employment that was organised by employment assistance agencies. Some participants had paid positions, such as delivering newspapers, butchering, washing dishes, and supermarket work, and others engaged in unpaid work. Discussions about employment reflected the pride that the respondents gained from their employment, especially from the money they earned. One participant explained, "I'm a groundsman...a groundsman means that's where you do so many jobs...It's good money though. Yeah. It's really good money. I get \$18...I get \$18.50 an hour" (Dorozenko et al., 2015, p. 1351). Other participants described the sense of purpose and meaning which their employment provides. Another area of discussion that was central to sense of self for the participants from this study was housing and welfare. Many of the participants received government financial assistance, which was described as insufficient and several had difficulties making their pension last each period. Some of the participants lived in government assisted housing and two individuals described their experience with homelessness while on the waitlist for government housing.

In a more recent study which examined sense of self among young adults with mild ID, Midjo and Aune (2016) found that housework was a dominant theme from some of their participants. For instance, one informant discussed the value that she gained from having cooking responsibilities in her household and described these skills as an investment for future independence. Another respondent who lived on her own identified her housework as being self-determined and a typical part of being an adult woman.

Typically, individuals with ID are dominantly seen as dependent, incapable, and lacking long-term hopes and dreams (Dorozenko et al., 2015), however the literature reveals that individuals with ID identify themselves as independent, capable individuals with goals and direction for the future (Midjo & Aune, 2016). For instance, in a study by Dorozenko et al. (2015), many of the participants talked about providing care to others. One respondent explained how he cares for his father who has dementia. Another participant discussed his role of providing care for his friend who has diabetes by reminding him to take his medications, have his insulin injections, and manage his daily sugar intake. Along with caregiving, in discussing sense of self, the participants described themselves as intelligent and competent. For example, one of the participants was informed and opinionated about the politics of his country, while another participant organised and facilitated a ceramics workshop for community members (Dorozenko et al., 2015). Last, the topic of personal growth was expressed. For example, one respondent explained, "How to describe myself? I think I'm a person who likes to be fair but likes to know more things as you go along. I like to grow in knowledge and understanding" (Dorozenko, Roberts, & Bishop, 2015, p. 1357).

# **Acknowledging Intellectual Disability**

Although much of the literature reveals that the sense of self of people with ID are ordinary and unrelated to having an ID, there are studies which indicate that having an ID impacts how people see themselves. In a study which explored sense of self in 51 adolescents with ID, over half of the respondents answered 'yes' when asked "do you have a disability?" (Jones, 2012, p. 35). From those who replied negatively, two individuals appeared to be embarrassed, three participants chose to skip the question, one noted that he used to have an ID and no longer does, and another explained that he sometimes has an ID. Out of those participants who stated they had a disability, some of the participants acknowledged and expressed a desire to change their ID in hopes to receive equal opportunities. For instance, one the participants explained; "I would be with no disabilities and actually get to be in regular classes and play football. Sometimes my disabilities just get old" (Jones, 2012, p. 35). Moreover, some of the respondents described their experiences and feeling towards abuse, stigmatization, and othering. For instance, one of respondents shared her feelings on her ID label, which she referred to as mental retardation (MR). She explained:

I hate being MR because people make fun of me. They call me names and laugh and talk behind my back. I also hate being MR because I have to ride a special bus and I do not function in the right classroom like others. I also hate being MR because you can't do what others do. You function at a different level. (Jones, 2012, p. 35)

Another participant addressed his position on his disability. He stated:

People try to convince me that I'm just like everyone else and get my confidence up, but I tell them I'm not and that I do have disabilities. That's probably why I don't make very much friends, but I'm used to it (Jones, 2012, p. 35).

Other participants seemed to disassociate themselves with others with ID in their classrooms. One respondent articulated, "It's a mistake. I should be in regular classes. I love them – the regular classes. It feels bad to be in special ed. classes because I feel bad about these people" (Jones, 2012, p. 35). Lastly, a few of the participants considered disability to only include physical disabilities.

Dorozenko et al. (2015) found that some individuals with ID acknowledged their ID when they described their sense of self, often with the recognition of being part of a marginalized or minority group. For instance, one of the participants referred to others with ID as "people in my situation" or "like me" (Dorozenko et al., 2015, p. 1352). Some of the respondents spoke of being a burden to their parents as they would often need to depend on their parents for financial support and transportation. Other participants applauded their parents for raising them "all on their own" (Dorozenko et al., 2015, p. 1352).

In the same study, some of the findings reflect a disdain from individuals with ID towards their ID label as it has caused them to lose autonomy over personal decisions. Dorozenko et al. (2015) found that parents and legal guardians often make decisions about the daily lives of their adult children. For example, one participant expressed sadness that she was unable to go to her favourite fast-food restaurant because her mother wanted her to lose weight.

The same findings reveal that another way that individuals with ID approach sense of self is describing their pride in proving naysayers wrong (Dorozenko et al., 2015). For example, one woman with ID took satisfaction in her abilities, which contradicted the grim prognosis her family received from medical professionals. She stated, "The specialist...actually said that I would never...well, they said that I would never talk but I've certainly proved them wrong" (Dorozenko et al., 2015, p. 1351).

Across the literature, researchers have found that individuals with ID often are unaware or simply do not acknowledge their ID in their sense of self (Beart et al., 2005). The literature also reflects the contradiction that exists among the quality of the sense of self among people with ID. One of the potential explanations of this from researchers is people with ID's lack of cognitive ability to develop awareness of social categories as well as the inability to connect personal challenges with professional discourse on disabilities (Beart et al., 2005). Similarly, Popovici and Buica-Belciu (2013) suggest that people with ID lack abilities that are identified as being pertinent for creating accurate sense of self, including basic cognitive, affective, behavioral, moral, and relational competencies. In addition, the same researchers also suggest that much of the information of individuals with ID is filtered and protected by their families, and might therefore lack realistic perspectives. However, most commonly discussed across the literature is that some individuals who do not acknowledge their ID label are indeed aware of their disability. Some individuals with ID deny or resist identifying with their disability in hope of avoiding stigmatization and being viewed as ordinary (Goffman, 1963; Beart et al., 2005; Jahoda & Markova, 2004). Midjo and Aune (2016) add that a major implication of resisting to identify with their ID is a decrease in appropriate supports for people with ID.

Throughout the research on the content of the sense of self in people with ID, there is a lack of discussion of leisure and its role in sense of self development. Perhaps this is due to the lack of enjoyable and meaningful leisure activities accessible to individuals in this population. Or perhaps this is due to the lack of recognition on the part of the broader research community about the value of leisure in people's lives.

## Leisure and Sense of Self

Although there is a lack of research conducted on the role of leisure, specifically among individuals with ID, the literature consistently states that leisure has a considerable influence on

sense of self among the general population. Researchers explain that leisure pursuits support individuals through the self-defining process (Kleiber, 1999).

Scholars in leisure studies cite criteria that categorize activities as leisure pursuits. First, leisure involves engaging in activities that provide a sense of perceived freedom and personal choice, rather than determined by external factors or demands (Hood & Carruthers, 2013; Stumbo & Peterson, 2009). Second, leisure activities result from internal motivations and fulfill intrinsic needs, such as self-expression, self-development, and meaning (Stumbo & Peterson, 2009). Third, engaging in leisure should offer people opportunities to develop self-efficacy. Fourth, leisure creates optimal experiences and positive emotion, including feelings of intense involvement, concentration, and notions of transcending self-consciousness and losing sense of time, known as states of flow (Stumbo & Peterson, 2009).

The literature explores the many benefits of leisure on well-being and overall quality of life. One of the main areas with which leisure can help individuals is physical well-being. Many leisure engagements involve physical activity, which studies have shown can improve overall physical health such as bone density, heart rate, and joint mobility, as well as reduce health problems including high blood pressure, heart disease, and secondary conditions (Stumbo & Peterson, 2009).

In addition to physical benefits, leisure pursuits can also support psychological well-being. According to Caldwell (2005) and Stumbo and Peterson (2009), engaging in leisure can improve the ability to prevent, cope with, and manage stress and negative life events. They also explain that leisure can help us develop self-identity, self-expression, and sense of freedom and control, as well as decrease symptoms of anxiety and depression. Additionally, Hood and Carruthers (2013) explain that leisure provides a sense of meaning, optimism, competence, self-

determination, and emotional regulation. Lastly, studies suggest that leisure can be therapeutic and help individuals cope with negative and traumatic life events by strengthening a sense of self-worth and helping people restore their inner-most selves (Caldwell, 2005).

Along with physical and psychological benefits, leisure can also contribute to our social well-being. Studies reveal that leisure provides an ideal context to develop social interaction skills as well as develop and maintain social support networks, create and nurture relationships, and develop social identities (Caldwell, 2005; Hood & Carruthers, 2013; Stumbo & Peterson, 2009).

Furthermore, studies show that leisure positively correlates with cognitive functioning. Research has demonstrated that personal development, social engagement, and community involvement result in cognitive development, all of which can be cultivated through leisure activities (Caldwell, 2005). Not only can leisure involvement enhance cognitive functioning, it can also lower risk of cognitive decline, such as dementia, later in life (Caldwell, 2005; Hood & Carruthers, 2013).

The literature suggests several ways that leisure can impact sense of self. Developmental psychologist, Erik Erikson (1963), outlines many factors that contribute to positive sense of self formation through six stages of psychosocial identity development. Some of these elements include creating a social network, being shown appreciation for performance, as well as building and acting according to one's belief systems, values and goals. Other elements include developing independence and self-confidence, engaging in intimate relationships, experiencing productivity and generativity, and having the ability to reflect on achievements, cease opportunities, and experience life satisfaction (Erikson, 1963). Furthermore, in an analysis of Erikson's stages of psychosocial identity development, Hamachek (1988) describes Erikson's

stages to include autonomy, gaining satisfaction from accepting new challenges and learning about new ideas, experiencing pride, and self-acceptance.

The literature on leisure and sense of self describes leisure pursuits as the prime context for youth to develop personal identity (Kleiber, 1999). Many of the factors that Erikson (1963) describes can be experienced through leisure activities (Stumbo & Peterson, 2009). Further research indicates that recreation has the potential to provide individuals with opportunities for exploration and commitment that is beneficial for building sense of self (Mannell & Kleiber, 1997; Marcia, 1993). The literature also stresses the importance of feeling able to express ourselves authentically in order to form positive sense of self (Erikson, 1969), which is commonly provided through leisure experiences (Stumbo & Peterson, 2009). Moreover, Kleiber (1999) suggests that leisure pursuits and personal interests provide a means for people to distinguish themselves from others, which can help someone define themselves more clearly and create a more positive sense of self. He further argues that because leisure inherently provides perceived freedom and is based on intrinsic motivations, leisure experiences offer people opportunities to develop sense of self.

Kleiber (1999) suggests that leisure activities can offer social experiences and provide people with opportunities to reflect on the perceptions and judgments of others. Furthermore, leisure pursuits can provide people with a context to engage in social comparison and performance feedback, which are significant to the process in shaping sense of self (Kleiber & Kirshnit, 1991; Mannell & Kleiber, 1997).

For leisure experiences to positively influence sense of self, the literature indicates that the leisure engagements should be pursued over a significant period of time, without becoming over-committed to the activity (Kleiber, 1999).

The literature on leisure and sense of self largely focuses on leisure among individuals with disabilities and illnesses. Charmaz (1994) explains that having a chronic illness can challenge the sense of self of individuals as valued attributes, abilities, and roles may be lost. Scholars argue that leisure can assist individuals with identity reconstruction, provide meaning (Reynolds & Prior, 2006), and opportunities to perform at their own level without influence from others (Ohman & Nygard, 2005). The research findings on the significance of leisure informing sense of self present benefits and constraints of leisure on the quality of sense of self.

## **Benefits**

The benefits of leisure on sense of self can be divided into the categories of personal development and social connection.

**Personal development.** There are numerous benefits of leisure pursuits related to personal development that support the construction of a positive sense of self. Such benefits can be divided into the categories of personal skills and traits, positive experiences, and self-awareness.

Skills and traits. According to Hamachek (1988), learning new skills, which can be done through leisure experiences, is a significant factor in the development of sense of self. In a study in which adolescents were interviewed about their participation in an outdoor adventure recreation program, Duerden et al. (2012) found that some of their respondents gained new competencies by participating in a new outdoor leisure activity. One of the informants commented, "You learn a lot and most of the stuff you probably will have to use later on at one point, [and] you can teach others how to do it" (Duerden et al., 2012, p. 192). In addition, in a study which explored the perceived outcomes of a community-based therapeutic recreation and adaptive sport program on the athletic identity of people with disabilities, findings indicate that

the participants gained new skills through engaging in therapeutic leisure pursuits, such as horseback riding or alpine skiing (Zabriskie, Lundberg, & Groff, 2005).

Along with developing new skills and traits, leisure engagements can also help people with acquired illnesses and disabilities maintain or rediscover valued skills and traits from their experiences prior to their diagnoses (Kleiber, Hutchinson, & Williams, 2002). Kleiber and colleagues (2002) reveal that such continuity can help such individuals establish a sense of self and reaffirm valued components of their former selves. For example, a study which explored the leisure experiences of older adults with early stages of dementia, found that individuals with dementia-related symptoms can continue to identify with certain aspects of their selves through leisure (Genoe & Dupius, 2011). One participant described a photo of her friend and her friend having coffee together by stating, "I've always been a people person so I think this is when you'll see me smile the most. When I'm with others" (Genoe & Dupius, 2011, p. 436). Another participant spoke about emphasising her abilities. She stated:

...I think leisure activities show um, that we still have a lot to give. Or even if um, I'm doing my crocheting or whatever, and that's exhibited, or I show friends what I've done. It's amazing. You know, especially when it comes to something I've never done before. So, I think in that aspect it's sort of like an advocacy. (Genoe & Dupius, 2011, p. 439)

This study also concluded that leisure can protect older adults with dementia from further decline. One participant for this study explained:

Yeah, it's replaced my work, my employment...Like I'm still very high functioning, but I have to alter what I do in leisure or work or just daily activities to sort of work on my weaknesses so I can enhance my lifespan of longer...and higher quality of memory.

Because what I do leisurely, quote work, either can enhance or decrease my memory loss. (Genoe & Dupius, 2011, p. 444)

These authors found that leisure replaced the skills and characteristics used in some participants' former professional roles. For instance, one participant who worked as a nurse, continued to exercise such associated lifelong traits through providing care for her cat and plants (Genoe & Dupius, 2011).

Self-confidence and pride. According to Erik Erikson (1963), self-confidence supports the formation of a positive sense of self. Research claims that leisure experiences can assist individuals with developing self-confidence. For instance, in the study by Duerden et al. (2012), many of the adolescents felt that their experience helped increase their self-confidence, which for some participants positively impacted their future experiences. Similarly, Boyce and Fleming-Castaldy's (2012) study, which explored active recreation for women with spinal cord injuries, indicates that leisure can enhance self-confidence. The sense of self of each woman appeared to embody more self-confidence following their participation in leisure. Respondents explained that this new self-confidence facilitated personal growth and initiation of new and exciting experiences. One informant testified:

It's not just playing a sport, it's a lifestyle. It's that two days a week that I can get out and hang out with people that are just like me, it's that I'm more social now. I never would have given a speech in front of 150 people and I did that last year. (Boyce & Fleming-Castaldy, 2012, p. 3661)

In another study which looked at the experiences of adolescents with disabilities in an adapted sports program, Groff and Kleiber (2001) found that 8 out of eleven participants developed self-confidence from their sport participation. One informant explained, "Basketball taught me a

lot...It's another thing to show me that I can do stuff that people who can walk do. I just do it in my own game" (Groff & Kleiber, 2001, p. 324).

Another way in which leisure benefits developing a sense of self is through providing individuals with a sense of pride and achievement, which contribute to a positive sense of self (Erikson, 1963; Hamachek, 1988). For instance, Duerden et al. (2012) had many participants discuss the pride they experienced when overcoming challenges, such as mountain-biking uphill. Another study that found that leisure offered opportunities for individuals to feel a sense of pride examined the experiences of adolescents with disabilities in an adapted sports program. Several of the participants in this study expressed pride from receiving positive feedback from others on their athletic achievements (Groff & Kleiber, 2001). Lastly, according to Genoe and Dupius (2011), older adults with dementia resist feelings of being purposeless and incapable by engaging in leisure activities that provide them with feelings of accomplishment, pride, and confidence.

*Positive experiences.* Along with developing personal skills, leisure can support the development of sense of self by providing individuals with positive experiences.

Studies found that leisure can provide individuals with positive emotion (Duerden et al., 2012; Stumbo & Peterson, 2009) and a sense of purpose and meaning (Stumbo & Peterson, 2009), which Erikson (1963) describes as significant for developing sense of self. For instance, a study which looked at the experiences of adolescents with disabilities in an adapted sports program, determined that adapted sports can provide adolescents with a sense of meaning in their lives. When asked how it would feel to not play sports, one participant responded, "I think that it would take a big part out of my life. The competitive part. You have to have a reason to want to live" (Groff & Kleiber, 2001, p. 326). In another study which explored the experiences of

individuals with cancer with visual art involvement, Reynold and Prior (2006) discovered that art can provide a sense of meaning for people with cancer, with one participant describing art as "a life-saver" (p. 336). Another participant described her artistic pursuits as something upon which she focused in her last few months of life. She explained, "When you're looking at a shorter life, rather than concentrate on that, you think 'I've got to get this finished' I think that helps a lot" (Reynolds & Prior, 2006, p. 337).

Sense of freedom. The literature indicates that a sense of freedom and autonomy are important to the development of a positive sense of self (Erikson, 1963; Hamachek, 1988) and can be attained through leisure pursuits (Hood & Carruthers, 2013; Stumbo & Peterson, 2009). For example, in a study which investigated meaningful aspects of participation in adaptive sports and recreation for individuals with disabilities, 14 of 17 participants discussed the sense of freedom that they gained from adaptive recreation activities (Lundberg et al., 2011). In this study, the word 'freedom' was used when discussing participants' experiences when they engaged in new activities. One participant discussed the sense of freedom with which skiing provided him. He stated:

First of all being able to [ski]...it's just kind of real free, independent kind of a feeling that I can't get any other way...There really isn't a boundary like there used to be. And now when I look at snow, I think whoa fun, instead of oh, I can't get around (Lundberg et al., 2011, p. 213).

The theme of freedom was often used in the literature in terms of freedom from disability. According to Dorozenko et al. (2015), individuals with disabilities often struggle to accept their disability as studies have shown that having a disability can negatively impact sense of self. A participant in the study by Lundberg et al. (2011) supported this argument during her

retelling of her experience with adaptive skiing. She stated, "It made me feel whole again, like I'm free. It's like I am skiing away from my wheelchair, that part of my life that makes me feel trapped" (Lundberg et al., 2011, p. 213). Another example relates to the sense of freedom that older adults with dementia can experience in leisure engagements. Genoe and Dupius (2011) determined that leisure provided a few of their participants with a sense of freedom to be carefree and relaxed. One participant from their study explained:

So, but, so the leisure, if I'm having a bad day, at what I call my work, then if I do something that's leisurely, like take a walk or do start something totally different that will bring me back to a point of a new beginning. (Genoe & Dupius, 2011, p. 442)

Positive choices. Research indicates that leisure experiences can be a catalyst for creating commitments and achieving goals, which contribute to creating positive sense of self (Mannell & Kleiber, 1997). For instance, in the study by Duerden et al. (2012), some participants explained that their positive leisure experiences have led them to seek out other positive experiences and make positive decisions. One respondent explained when discussing the impact of the leisure-based camp, "I used to just mess around and not really do anything at home and stuff, but now I'm thinking of all these things I should go and do instead" (Duerden et al., 2012, p. 194).

Similarly, Groff and Kleiber (2001) reported that a few adolescents with disabilities, who were interviewed about their experiences with an adapted sport program, found that the skills that they gained from playing sports motivated them to consider playing sports at the collegiate or international level.

*New experiences*. One aspect that can be involved in both leisure experiences and building a positive sense of self is having new experiences (Erikson, 1963; Hamachek, 1988; Mannell & Kleiber, 1997). For instance, many of the participants in the study by Duerden et al.

(2012) noted that new experiences, such as white-water rafting, became memorable and exciting because of their novelty.

Leisure can also provide people with acquired illnesses with new leisure pursuits. For example, Genoe and Dupius (2011) learned that older adults with initial stages of dementia can gain positive emotion and engagement from new leisure pursuits. One of the participants from this study explained her newfound interest in reading. She stated:

I've never been a reader but it's given me a new extension, and it's a new extension of leisure that I can take the book with me if I'm at a doctor's office, if I'm going to visit someone, I can take it with me. Um, it's just opened another whole field. (Genoe & Dupius, 2011, p. 440).

Self-awareness. Leisure can positively influence sense of self by supporting individuals to develop self-awareness. According to Kleiber (1999), identities can be formed through experimenting with and elaborating on personal interests, which leisure engagements can help manifest. Leisure can also offer individuals an opportunity to spend some time away from their daily responsibilities. This can provide people with a platform for personal reflection, which can offer an opportunity for individuals to think about the way they see themselves (Kleiber, 1999). Similarly, findings also indicate that leisure can provide people with opportunities for emotional expression and emotional regulation (Boyce & Fleming-Castaldy, 2012; Zabriskie et al., 2005), which supports the development of sense of self. Moreover, leisure can provide people with an escape and solace from everyday life as well as release tension from stressful events (Boyce & Fleming-Castaldy, 2012). Additionally, Minar (1999) argues that art-making can support people with cancer to discover inner resources. For example, in a study which aimed to understand how visual art-making might help people with cancer reconstruct how they see themselves, Reynolds

and Prior (2006) found that engaging in art gave individuals an escape from their challenging reality. One participant from their study explained how art helped her cope with chemotherapy by allowing her to engage in deep concentration and distract her from discomfort and fear.

The literature also presents findings that specifically describe the ways in which leisure can help individuals develop self-perceptions and sense of self (Caldwell, 2005; Stumbo & Peterson, 2009). For instance, Duerden et al. (2012) found that many of his participants directly commented on the new self-perceptions they gained from their leisure experiences. Some of the participants commented on new-found qualities, such as bravery and strength, which they felt they gained from such leisure experiences. One adolescent stated:

Because I'm heavier, some of the things that I think that other people can do, like sometimes I feel like I can't do it and I can't complete it. But today and the past few days I felt that like I can do what other people do if I just keep on trying on hard and taking risk[s] and even though you think you can't do it you really can and you just keep on trying. (Duerden et al., 2012, p. 193)

Additionally, leisure's role in constructing self-perceptions is evident in a study which discovered the experiences of active recreation for four female athletes with spinal cord injuries. An emerging theme was regaining a sense of self following their injuries. For instance, one women stated, "[I] found out that I could work out with weights and get that powerful feeling, that confident feeling and just feel like a little bit more of me was back" (Boyce & Fleming-Castaldy, 2012, p. 365).

Research suggests that leisure can provide individuals with a strong sense of self, even when experiencing functional losses from illness or disability (Genoe & Dupius, 2011). For example, in the study on leisure and people with dementia, one participant found that leisure

provided her with a sense of individuality and self-worth, despite her experiences with memoryloss (Genoe & Dupius, 2011).

Some of the literature explains that developing a sense of self involves self-expression (Erikson, 1969), which leisure provides opportunities to create (Stumbo & Peterson, 2009). For example, in a study which looked at the experiences of adolescents with disabilities in an adapted sports program, Groff and Kleiber (2001) found that leisure allowed a couple of the participants to express their anger and aggression in an acceptable way, particularly anger towards their disabilities. In addition, studies have shown that art involvement assists people with cancer with expressing fears and reducing feelings of helplessness (Minar, 1999).

Connection. Along with personal development, leisure can support the cultivation of a healthy sense of self through establishing connections with others. Building a sense of self greatly relies on social connection as it is the feedback from others that contributes to forming a sense of self (Erikson, 1963; Shavelson et al., 1976). Social connections are often achieved through leisure experiences, which can directly inform how we perceive ourselves (Kleiber, 1999). The literature focuses on two main social benefits of leisure on the sense of self: belonging and social connections.

*Belonging.* Social groups can provide individuals with a sense of belonging and identity in relation to others (Kleiber, 1999). The literature maintains that leisure develops and fosters social support networks, social identities (Hood & Carruthers, 2013; Stumbo & Peterson, 2009), social engagement, and community involvement (Caldwell, 2005). According to Erikson (1963), building a social network is a key factor in nurturing a sense of self. Kleiber (1999) explains that leisure pursuits, which can help facilitate social connection, encourage natural interactions with those with whom we may identify and share patterns of actions. Furthermore, adopting similar

formal and informal dress, customs, and codes of conduct with others in the same activity can further bond individuals together (Kleiber, 1999).

The literature argues that group identification impacts one's social identity as well as sense of self, which are often based on the social meaning that can be attributed to a particular leisure pursuit (Tajfel & Turner, 1979). Involvement with a group and communal identity can often bring about a sense of personal identity and belonging (Taylor, 2003). Throughout the literature, the idea of belonging was particularly addressed among studies that involve individuals with disabilities and illnesses. For example, in a study which explored the experiences of 17 individuals with disabilities during their participation in adaptive sport and recreation, Lundberg et al. (2011) found that many of the participants gained a sense of community and acceptance from their peers. These individuals felt that the group recreation context offered them opportunities to meet others with disabilities, which gave some of the informants a feeling of support and identification. One participant affirmed:

I think it has given me the knowledge that, hey you are not the only one in this situation. There are others in this situation, perhaps even worse that you, or better than you, but there are others experiencing this challenge in life along with you. The support system is huge! And just knowing that there are others out there that you can lean on is a great thing. (Lundberg et al., 2011, p. 213)

Furthermore, in a study which examined the experiences of adolescents in an adapted sports program, many of the participants felt positively about the opportunity to socialize and relate with others with disabilities. One informant remarked:

They can find stuff funny about the fact that you got a flat tire in band, you know. They understand that and they laugh about that. And other people, people without disabilities,

they don't get it, or they don't find it as funny as it really is. They appreciate the stuff you are going through. (Groff & Kleiber, 2001, p. 326)

Lastly, Reynolds and Prior (2006) found that art provided individuals with cancer with a social network. One participant's involvement in cross stitching and card making became an opportunity to create community through offering classes and selling her art to raise money for charity, which reduced the focus of illness in her life (Reynolds & Prior, 2006).

Social acceptance. For many individuals with disabilities and illnesses, social acceptance and freedom from stigmatization supports the cultivation of a positive sense of self. For instance, research has proven that stigmatization lowers self-esteem among people with ID (Paterson et al., 2012). Furthermore, Paterson et al. (2012) provide evidence that people with ID can internalize perceptions of stigmatization, which can negatively impact the way they see themselves. Moreover, Mannell and Kleiber (1997) describe social comparison to be an important aspect of sense of self formation and Paterson et al. (2012) describe it to be important to the experience of stigmatization. This connection between stigmatization, self-esteem, and sense of self implies that experiencing stigma can have a negative impact on one's sense of self. Thus, experiencing freedom from stigmatization can create more positive sense of self among people with disabilities.

The literature supports the provision of social acceptance and reduced stigmatization through leisure pursuits. For example, according to Groff and Kleiber (2001), sports can positively impact sense of self among youth with disabilities through social interaction, connection, and normalization of disabilities. Furthermore, research indicates that outcomes of community-based therapeutic recreation and adaptive sport programs are likely to bridge the gap between individuals with and without disabilities (Zabriskie et al., 2005). In the study by

Lundberg et al. (2011), leisure participation helped participants to feel equal to people without disabilities. One participant with spina bifida explained, "Just being able to find something that I can do well and that I can do with other people on an athletic level has made a huge difference for me. When I am skiing with able-bodied people, I'm their equal" (Lundberg et al., 2011, p. 214).

Not only does the literature reflect the sense of social acceptance that is often gained among people with disabilities and illnesses who participate in leisure, research findings discuss the sense of normalcy that leisure experiences may bring to people's illnesses or disabilities as well. For example, in the aforementioned study, almost all of the respondents reported that adaptive recreation participation provided them with a context in which they felt that they fit in with the status quo and their disabilities did not make them different than others (Lundberg et al, 2011). One respondent explained her experience with adaptive recreation by stating, "It helped me to get over the fact that I was in a chair and realize that I'm just as normal sitting as someone is normal standing, or without sight, or anything" (Lundberg et al, 2011, p. 215).

Social connections. Along with a sense of belonging, leisure can also provide people with social connections that can support constructing a sense of self. For example, Erikson (1963) describes intimate relationships to be a contributing factor towards positive sense of self. The literature states that building nurturing relationships and the related social interaction skills can be achieved through leisure activities (Caldwell, 2005; Hood & Carruthers, 2013; Stumbo & Peterson, 2009). For instance, Duerden et al. (2012) discovered that leisure provided these individuals with supportive relationships with both peers and recreation staff. One of the participants in their study noted that he felt supported from the staff as they motivated him to push through obstacles during leisure activities when he wanted to quit. Furthermore, the sense

of self-worth and value that many of the informants felt from others is noteworthy as well (Duerden et al., 2012).

Research indicates that active recreation can positively contribute to feeling valued by others (Boyce & Fleming-Castaldy, 2012), which the literature claims is an important element of creating a positive sense of self (Erikson, 1963). For example, in a study that explored the experiences of women with spinal cord injuries and their participation in active recreation, Boyce and Fleming-Castaldy (2012) discovered that the women consistently reported that the positive feedback they received from others, including peers, reinforced their positive sense of self.

In addition to supportive relationships between staff and peers, another theme in the literature that can positively impact the sense of self, is role model relationships. For instance, in the previously mentioned study Boyce and Fleming-Castaldy (2012) discovered that all their participants discussed the value of being recognized as role models to significant others, teammates, and individuals within their communities. An example is in one respondent's comments:

People that know me and have seen when I've done since the disability...they just are amazed by what I'm physically able to do and just my mental attitude about being positive and enjoying life despite obstacles and challenge, and sometimes overwhelming insurmountable looking odds or barriers. (Boyce & Fleming-Castaldy, 2012, p. 368)

Another example of leisure providing individuals with social connections with peers is shown in a study which looks at the involvement of adolescents with disabilities in an adapted sports program. In this 2001 study, Groff and Kleiber found that sports allowed their respondents to meet and connect with peers with similar interests and experiences.

Studies suggest that leisure can also connect people with their family members. For instance, in a study which looked at older adults with mild dementia and their experiences with leisure, Genoe and Duprius (2011) found that some of their research informants experienced connection with their grandchildren through mutual leisure activities. Not only did these experiences allow the older adults to share their experiences with dementia and connect with their family and world around them, but it also provided them with perspective and acceptance towards their dementia diagnoses (Genoe & Dupius, 2011).

# **Constraints**

The literature also outlines various negative impacts that leisure can have on one's sense of self. According to Keibler (1999), leisure may negatively impact sense of self if leisure pursuits do not reflect one's personal interests and strengths or the commitment to a recreation activity becomes so consuming that it overtakes other aspects of life. Kleiber (1999) also states that leisure can have negative outcomes on one's sense of self if the leisure activity causes discouraging or other negative perceptions of the self.

Gender and racial stereotypes. One aspect that has been said to challenge peoples' sense of self is gender norms and stereotypes within leisure activities. For instance, there can often be a conflict between how women in sports view themselves and how society views women in sports (Snelgrove, 2015). Green and Chalip (1998) have indicated that gender stereotypes in sports can negatively affect women's ability to use sport as a means of constructing their sense of self. Similarly, the literature mentions that there can be a comparable conflict within leisure pursuits and racial norms and stereotypes. Specific racialized leisure activities have been stereotypically prescribed to certain racial groups, which can create clashes

when forming a sense of self (Appiah, 2000). One example of this is the sport of basketball among African Americans, particularly those in inner-cities (Ogdon & Hilt, 2003).

**Stigmatization and exclusion.** Additionally, findings have shown that individuals with disabilities and illnesses have experienced negative influences from leisure experiences as well. For instance, researchers Devine and Lashua (2002) found that during recreation activities, some individuals with observable disabilities experience exclusion and intolerance due to their method of executing physical tasks. Although physical leisure activities typically have a positive impact on people (Blinde & McClung, 1997), studies reveal that individuals with physical disabilities may develop body image issues due to receiving negative feedback from others on their physical appearance in leisure settings (Fox, 1990). Other researchers confirm that there is a lack of reciprocity between people with and without disabilities within leisure venues and some inclusive recreation settings aiming to increase awareness, might create more exclusion of individuals with disabilities (Devine & Parr, 2008). Additional research explores leisure negatively impacting sense of self in the context of women's experiences of disabilities in sport. In this study, participants state that they feel frustration due to a lack of physical accessibility among recreation venues, a lack of recreational opportunities available for people with disabilities, as well as a lack of support for disabled women's sports in our society (Boyce & Fleming-Castaldy, 2012). The same study also explores emotional constraints, which can negatively impact the sense of self of individuals with disabilities. For instance, one participant described feeling self-conscious that she had to modify exercise equipment in gyms.

**Illness and disability-related constraints.** The final constraint that leisure may pose is a direct result of having an illness or disability. In a study which examined the ways in which leisure influences identity development among youth with chronic illnesses, Snelgrove (2015)

found that leisure often is challenging and causes participants with illnesses to feel frustrated from experiencing significant weight changes. For instance, some of the respondents explained the pain, lack of energy, and low self-esteem due to illness-related weight gain when involved in physical activity or leisure pursuits that showcase one's body. The same researcher found that individuals with chronic illnesses sometimes feel as though leisure has become a place of concern for them as they fear embarrassment from showing symptoms of their illness among others. Additionally, Snelgrove (2015) found that certain leisure pursuits may pose constraints for people with chronic illness. For instance, social activities involving alcohol consumption may be difficult to navigate for individuals who have illnesses that do not allow them to consume alcohol. Lastly, leisure performance, particularly youth sport, that does not meet the expected level of success for certain individuals may lower their self-esteem and ultimately may negatively impact their sense of self (Coakley, 1992). As well, youth who rely on their success in leisure performance, may reduce their explorations in other domains, which can place constraints on creating a multidimensional sense of self (Kleiber & Kirshnit, 1991).

### **Intellectual Disability and Leisure**

Leisure can benefit everyone, including, if not especially, those in marginalized populations, such as individuals with ID. Despite the unique challenges that people with ID can often experience, many people in this population lead happy, meaningful, and rich lives. Similar to individuals without ID, one of the ways individuals with ID maintain good health and a high quality of life is through participation in leisure (Badia, Orgaz, Verdugo, Ullan, & Martinez, 2011; Paez & Farber, 2012). Moreover, research has shown that engaging in leisure can help people with disabilities overcome disability-related and societal challenges (Badia et al., 2011). Unfortunately, many individuals with ID face barriers to leisure, which negatively impact their

health and quality of life (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006; Taylor & Jozefowicz, 2012).

People with ID engage in positive leisure lifestyles. According to Wilhite and Keller (1996), since the shift from individuals with ID living in segregated institutions into living and participating in mainstream communities, there has been considerable research done on the leisure lifestyles of such individuals. The characteristics of leisure lifestyles of those with ID look similar to those of people without ID, however there are some differences. Additionally, people with more mild disabilities often experience a wider range of leisure pursuits than those of people with more severe disabilities (Van Naarden Braun et al., 2006). Research on the characteristics of the leisure engagements of people with ID highlight leisure preferences, satisfaction, values, and trends.

While there are significantly diverse interests among people with ID, there are various leisure preferences that are common. Some studies suggest that passive leisure activities, such as playing computer games or watching movies, tend to be common among people with disabilities. For example, in a recent study which examined the leisure preferences of youth with severe disabilities, out of the 12 participants, 11 spent their leisure time in passive leisure pursuits, such as watching television (King et al., 2014). Researchers have suggested that passive leisure pursuits are common among people with disabilities partly due to potential cognitive and communication impairments, which can make it difficult to make and/or express choices and often result in having leisure decisions made on their behalf (Bache & Derwent, 2008). Another partially passive leisure pursuit that is popular among this population is going to movies theatres. A 2008 study suggests that 42 percent of people with disabilities in the United States regularly go to movie theatres (Barnes & Mercer, 2006). Beyond passive leisure pursuits, activities that

involve more physical aspects, such as walking, are considered to be relatively common among individuals with ID. For instance, a recent study, which examines the leisure preferences of adults with disabilities in Poland, suggests that 37 percent of their subjects declare that they walk once a week while 10 percent walk daily (Taylor & Jozefowicz, 2012). Active leisure activities are less common among individuals within this population. For instance, a study which looked at the leisure choices of youth with disabilities over the span of two weeks found that only 13 percent of participants played an organized sport during this time (Van Naarden Braun et al., 2006). Another example is in a more recent study that looks at the leisure preferences of 12 individuals with disabilities, which suggests that only two participants chose to work out or attend a fitness class (King et al., 2014).

In addition to active and passive leisure, the leisure preferences of people with ID can also be analyzed in terms of engagements that are done individually or socially. Although people with ID generally participate in fewer social leisure engagements than people without ID, the literature on the leisure preferences of this population suggests that people with ID engage in a considerable amount of social-related leisure (Van Naarden Braun et al., 2006). For example, among youth with and without disabilities in the same study, 72 percent of the participants with disabilities socialized with friends over the two-week period, compared to 90 percent of those without disabilities (Van Naarden Braun et al., 2006). Similarly, almost 60 percent of the respondents with ID in a 2012 study spend their leisure time with family and friends (Taylor & Jozefowicz, 2012). Furthermore, in a more recent study, 83 percent of its participants with disabilities engaged in leisure pursuits that involved other people (King et al., 2014).

Another valuable element of the leisure lifestyles of people with ID is leisure satisfaction.

Paez and Farber (2012) assessed leisure participation and desire among 22,000 Canadian adults

with disabilities, and propose that most Canadians with disabilities feel dissatisfied with their leisure lifestyles and generally wish to engage in more leisure activities.

Along with the leisure preferences and satisfaction of individuals with ID, the literature presents several common leisure values. A study which examined the leisure values of 12 young adults with disabilities reported that it was important for the participants that their leisure experiences provide a sense of belonging, fun, control, and choice (King et al., 2014). The first theme of belonging and engagement with others included being supported, valued, and encouraged by others. It was evident in this study that sharing leisure experiences with others was sought after by the participants more than the actual leisure activity. King et al. (2014) explain:

Participants wanted opportunities to socialize and be in the world. Although they wanted opportunities to engage in activities that were "fun" and worthwhile, socializing with significant others or just being around other people away from home...was at least as important. (p. 1631)

The second value of enjoying the moment and having fun was highly connected to sensory stimulation, like traveling quickly in wheelchairs outside and demonstrating competency. Another important part of leisure that arose for some of the participants was the involvement of risk and feeling free in their activities, while others preferred safer environments (King et al., 2014). The final important value that emerged was having control and choice in the selection of and participation in activities, which contributes to an overall sense of independence and autonomy (King et al., 2014).

With the development and accessibility of computers, computer-based leisure has become popular among individuals with disabilities (Bache & Derwent, 2008). Because many

people in this population often engage in passive leisure pursuits, computers and other assistive technologies have increased the range of passive leisure activities and have included other beneficial domains, such as social interaction through social media, e-mail, and chatrooms, creative expression through blogs, as well as education through distance-learning opportunities (Bache & Derwent, 2008).

### **Benefits**

There are many benefits to leisure for people with ID, just as there are for people without ID. Studies reveal that leisure participation benefits the overall health and quality of life of individuals with ID (Badia, Orgaz, Verdugo, Martinez, & Ullan, 2013). For example, past research has shown that participation in leisure activities supports people with developmental disabilities to become integrated into the community and develop adaptive skills (Duvdevany, 2002; Van Naarden Braun et al., 2006).

The literature indicates there are psychological benefits to leisure participation among people with ID, including exercising autonomy and emotional regulation (Badia et al., 2011; Hood & Carruthers, 2013). For instance, studies have revealed that people with developmental disabilities can become more self-determined through engaging in leisure due to the opportunities to be autonomous (Badia et al., 2011), which are rare among people in this population (Patterson & Pegg, 2009). Furthermore, leisure engagement among people with ID has been proven to reduce rates of depression (Bache & Derwent, 2008)

The literature identifies several social benefits of leisure participation for individuals with ID. Leisure can help develop social networks through community inclusion and integration between people with and without ID, which helps to reduce stigmatization (Datillo et al., 2008)

#### **Barriers**

Individuals with ID experience many barriers surrounding leisure participation due to both disability-related factors as well as external factors.

**Disability-related barriers.** Research suggests that limitations that are caused by disability can cause challenges to participate in leisure activities (Van Naarden Braun et al., 2006), particularly with visiting friends and physical leisure activities (Paez & Farber, 2012). Other possible ways that disability can impede on leisure engagements is a perception of not having enough time and/or energy (Badia et al., 2011).

Among the disability-related barriers to leisure for people with ID, studies suggest several barriers that exist specifically surrounding relying on personal support staff. For instance, barriers can develop when personal support staff do not initiate leisure activities for clients (Badia et al., 2011).

**External barriers.** In addition to disability-related barriers, people with ID often experience barriers to leisure that are based on external factors. The literature stresses the many obstacles surrounding accessibility and mobility, including barriers related to transportation, infrastructure, and accessible leisure facilities (Taylor & Jozefowics, 2012). For example, studies reveal that requiring the assistance of a personal support staff while mobilizing is associated with a decline in leisure participation for individuals with disabilities, possibly due to the difficulties of regularly relying on another individual (Paez & Farber, 2012).

Additionally, stigmatization acts as a barrier to leisure participation for people with ID (Badia et al., 2011). Due to stigmatization towards ID, the leisure activities that are often offered to people with ID are few and often stereotypical activities, such as bowling and arts and crafts (Van Naarden Braun et al., 2006).

Because disability-related factors can create major barriers to creating accurate and positive sense of self among people with ID, this study will partly be approached using a therapeutic recreation lens.

# **Therapeutic Recreation**

With the increase of studies conducted in the field of leisure, researchers and practitioners are continuing to understand the importance of cultivating optimal daily leisure engagements. Research suggests that engaging in leisure experiences that are authentic, gratifying, and meaningful, increases perceived quality of life and well-being (Hood & Carruthers, 2007). However, leisure is often overlooked or denied, which can have negative consequences to our quality of life. This reality is especially true for many individuals within vulnerable populations, including low income populations, single-parent families, older adults, and people with disabilities (Paez & Farber, 2012).

Despite growing awareness, there is still a need to support the cultivation of positive leisure lifestyles among many individuals, which can be done through different processes including therapeutic recreation. Therapeutic recreation (TR) is defined as "a systematic process that utilizes recreation and other activity-based interventions to address the assessed needs of individuals with illnesses and/or disabling conditions, as a means to psychological and physical health, recovery and well-being" (National Council for Therapeutic Recreation Certification [NCTRC], 2016, "About Recreation Therapy", para. 1).

Within the broader discipline of leisure studies, TR aims to assist people, particularly those in special populations, such as people with disabilities, in improving their quality of life through leisure (Hood & Carruthers, 2013). Along with further expanding the research within leisure studies, as well as continuing to increase awareness of individuals with disabilities,

providing more TR services in communities can support people with disabilities to engage in leisure lifestyles that cultivate positive quality of life (Wilhite & Keller, 1996).

Stumbo and Peterson (2009) explain that there are countless modalities through which TR can be practiced. A common therapeutic recreation modality is dance.

# **Intellectual Disability and Dance**

The literature argues that dance can support individuals with ID. According to Beardsley (1982), dance can be defined as "a motion, or sequence of motions, [that] does not generate practical actions, and is intended to give pleasure through perception of rhythmic order" (p. 35). Dance embraces what it means to live in the world and to express our experiences of life (Block & Kissell, 2001). Dance scholars argue that people are natural movers, which can be evident by toddlers organically bouncing and shaking to music and nursery rhymes (Oliver & Hearn, 2008). Furthermore, everyone can dance, regardless of age or abilities (Oliver & Hearn, 2008). In addition, dance is a natural bodily expression, which, like other bodily expression, has been repressed in Western society (Block & Kissell, 2001). Historically, dance has been used for communal and social expression, often during a celebratory or mournful occasion (Buckland, 2006). Today, this art form is sometimes viewed as something that is inaccessible, when is reality, dance is a natural form of self and communal expression. Block and Kissell (2001) explain:

Even today we dance the passage of life's happy stages at bar mitzvahs, proms and weddings. And although we seldom dance ceremoniously at funerals and divorces, our bodies react by perhaps becoming numb or doubled over in grief; this is the 'essence of dance'. (p. 13)

Today, people dance in many different settings with various intentions. Along with

social dancing, including that which is done at parties, dance can also be taught recreationally or competitively through education curricula, private dance studios, or other community settings, as well as pursued professionally (Oliver & Hearn, 2008). Furthermore, there are countless dance styles, both common dance genres which are internationally recognized, such as ballet, jazz, and hip hop, and cultural and folk dances, like the Philippine dance called Tinikling (Oliver & Hearn, 2008).

There are various benefits of dance. The physical benefits of dance include balance improvement through exercising the vestibular system (Oliver & Hearn, 2008). In addition, dance improves focus, concentration (Stinson, 1997), and the development of cognitive strategies (Giguere, 2011). Furthermore, dance can enhance emotional well-being in many ways, including building confidence (Oliver & Hearn, 2008), relieving stress, and cultivating excitement (Stinson, 1997). Lastly, the physiological benefits of dance include developing a sense of self and connecting with individuals' true or inner selves as well as providing people with a sense of freedom, transcendence, and a loss of the outside world (Stinson, 1997).

### **Recreational Dance**

Definitions like who a dancer is and what a dancer might look like are gradually becoming more inclusive. According to Block and Elkins (2006), "If the dance process is planned properly, exceptionally skilled dancers, dancers with average skill, and persons with disabilities can all display their skills in a creative, artistic, and recreational manner, both in and outside the classroom" (p. 16). This growing acceptance of dancers with a range of abilities invites more opportunities for people with ID to engage in dance in a variety of settings. Today, dance opportunities for people with ID, typically in more populated cities, are becoming more diverse.

According to the literature, recreational dance programs typically consist of community-based recreational dance classes, often offered in private studios or community centres, and school curriculum-based recreational dance classes. Community-based recreational dance classes for students with disabilities are usually geared towards children and youth and are typically small in class size (Nelson, 2017). Furthermore, although dance is often naturally therapeutic, many community-based recreational dance classes for students with disabilities are focused on teaching dance, while providing students the opportunity for an artistic and creative experience (Nelson, 2017). In addition, similar to other community-based recreational dance classes, such classes for students with disabilities are comprised of elements including warm-ups, improvisation, technique and motor skills, choreography, and cool downs (Nelson, 2017).

In addition to community-based recreational dance programs, dance education is sometimes offered as part of the Canadian school curriculum either as a component of physical education or as an independent class (Francis & Lathrop, 2014). Independent dance classes in the education system promote an appreciation of dance as an art form and engage students in a creative and participatory way (Whyte, 2013). The Canadian educational systems promote inclusion of students with disabilities in general education classes as much as possible (Thompson, Lyons, & Timmons, 2015).

Researchers explain the values of dance performance for an audience. According to Block and Johnson, (2011), performances provides students with a context to apply learned dance skills, which is a key component of dance pedagogy. Additionally, performing dance, in any venue, can develop a sense of passion, professionalism, and unity in dancers, which is important for complete dance integration. Furthermore, the literature suggests the technical level

of the performance compliments that of the performers. For example, beginner dancers might start performing in class for other students (Block & Johnson, 2011).

### **Benefits**

According to the literature, recreational dance can offer many benefits for individuals with ID, which can be described in terms of physical, social, psychological, and cognitive benefits.

**Physical benefits.** Engaging in recreational dance can provide many physical benefits for people with ID. According to Barnet, Perez-Testor, and Guerra (2013), dance can improve the kinesthetic awareness of individuals with ID. Additionally, significant research has been conducted on the physical benefits of recreational dance engagements for individuals with Down syndrome. Dance can increase physical activity (Evenhais, 2001), which combats the sedentary lifestyle commonly associated with individuals with Down syndrome due to lack of access to leisure participation (Barnhart & Connolly, 2007). In addition, Moraru, Hodorca, and Vasilescu (2014) suggest that dancing can improve the stability and strength in major muscles groups in individuals with Down syndrome. Furthermore, research indicates that dance offers a more selfexpressive and creative way of improving physical activity, which can make it a beneficial and effective leisure pursuit for individuals including those with ID (Jobling, Virji-Babul, & Nichols, 2006). Other research indicates that dance can improve physical balance and coordination in individuals with Down syndrome (Reinders, Bryden, & Fletcher, 2015). Another benefit that dance can offer people with Down syndrome is an increase in blood flow and endorphins in the body which can fight against various disorder-related symptomatology that are common among people with Down syndrome (Evenhuis, 2001), such as hypothyroidism (Barnhart & Connolly, 2007). Lastly, dance can increase cardiovascular capacity, increasing muscle mass, decreasing

body weight, strengthening bones (Clark, 2011), which are common physical health-related goals for people with Down syndrome (Barnhart & Connolly, 2007).

Social benefits. Along with physical benefits, there are many social benefits that people with ID can gain by being involved with recreational dance. According to Ashwill (1992), dance provides people with ID a platform to gain access and equal rights to leisure pursuits as well as developing awareness and advocacy for the disability population. Additionally, community programs, including dance programs, offer opportunities for socialization and social skill development (Becker & Drusing, 2010). For instance, based on a 2010 case study which looked at the impact of a community performing arts program on an individual with Down syndrome, Becker and Drusing concluded that their subject experienced a decrease in anxiety in social settings. Another case study describes an individual with Down syndrome being more socially engaged and communicative during and following involvement in a community recreational dance program (Reinders et al., 2015). Clark (2011) partly attributes social skills development in community dance programs to the use of teamwork when dancing with others such as creating choreography in groups.

In addition to supporting inclusion, socialization, and social skills development, the literature suggests that community dance experiences can also promote peer acceptance for individuals with ID. Zitomer's research (2016) explored the experiences of children with disabilities in an inclusive elementary school dance education program. One of the children stated, "I liked being a leader because I remember them (the moves), and because people listen to me. And people don't always listen to me too much. But they do in dance" (p. 224). These participants felt recognized and appreciated by their peers, with and without disabilities, which supports the positive effect of inclusion. The data explained that the specific skills used to

effectively participate in dance classes allowed peers to see the strengths of the research participants, which might not have been showcased in other classes. Lastly, dance experiences can assist individuals with ID to develop a sense of social responsibility. Community-based dance classes require participants to employ social responsibility through class elements such as working with others to achieve the same goals, and a sense of commitment is often needed to learn and master dance technique (Block & Johnson, 2011).

**Psychological benefits.** Along with physical and social benefits, community dance programs also offer psychological benefits for people with ID. One of the psychological benefits of dance for people with ID is the cultivation of positive emotion. For instance, Zitomer (2012) explored the experiences of eight children with disabilities with elementary school dance education; she found that all of them experienced positive emotion from dancing as well as half of them described the dance class as their favourite class. Another psychological benefit that dance can provide individuals with ID is support with healthy emotional expression. According to Block and Johnson (2011), the freedom and creativity of dance invites emotional expression for people with disabilities. Another researcher describes dance to be a useful emotional outlet as dance is a style of communication for individuals with Down syndrome (Clark, 2011). Furthermore, dance can enhance self-esteem and self-efficacy among people with ID. Studies reveal that dancers with disabilities felt empowered by learning and performing dance (Ashwill, 1992; Band et al., 2011; Whatley, 2007). In addition, Cone (2015), who advocates for the beneficial role that dance can play in self-efficacy development, states, "when students with disabilities have access to dance whether it is in a P-12 school environment, a private studio, or a community program, they learn that there are no limits to what they can learn and do" (p. 85). Moreover, a case study which explored the experiences of an individual with Down syndrome in

a community dance program, indicated that dance increased the self-esteem and confidence of one of their research participants when his peers clapped and cheered for him in a dance circle at the end of each class as well as when others would complement him on his dancing (Reinders, 2015). In the same study, the dance instructor supported this argument when she commented, "[There is a] change in self-confidence in the students and you know them [they are] growing as a person and believing in themselves. And realizing um their own potentials is what's I would say the biggest reward, whether they know it or not" (p. 299).

Along with dance enhancing the positive emotion, emotional expression, and self-esteem of individuals with ID, studies show that dance can also develop a sense of self, self-acceptance, and self-love in people with ID. In a study by Harmon (2015) which explored concepts related to inclusive performance dance, one of the respondents, who was a dance performer, explained how dance provided him/her with the opportunity to construct a sense of self, both for himself/herself and others. In the same study, the researcher explains, "by expressing themselves through dance, our respondents affirm themselves as subjects entitled to respect and the full enjoyment of rights and opportunities, and additionally, as uniquely abled individuals with particular and valuable talents" (p. 494). In addition to developing a sense of self, studies indicate that dance can promote a sense of self-acceptance. For instance, in a study which examined the impacts of grounding exercises on older adults and adults with ID within a dance movement therapy context, researchers De Tord and Brauninger (2015) explain, "these simple grounding exercises allowed both the older people and the adults with ID to accept and connect with their bodies, with themselves and their reality" (p. 20). Lastly, dance can cultivate a sense of self-love in people with ID. For example, in research published in 2011, Block and Johnson reveal that dance

can provide individuals with disabilities an opportunity to discover their value within a group dance context.

Cognitive benefits. The final area that community dance programs can benefit people with ID is within the cognitive domain. The literature suggests that engaging in community dance programs promotes intellectual development in people with ID. For instance, according to Block and Johnson (2011), dance students with ID must remember the names of other people in the class as well as the choreography and musical cues. The final cognitive benefit of dance for individuals with ID that the literature mentions is improvement with problem solving skills (Jobling et al., 2006).

#### **Themes in Dance Literature**

There are several major themes that are discussed in the literature on dance and individuals with ID. First, the concepts of inclusion and exclusion of people with ID in dance spaces were explored. Second, identity was also examined in the literature.

Inclusion/exclusion. According to Block (2008), dance experiences can generate the normalization of peoples' differences and abilities. Many dance classes provide an opportunity for the instructors and dance students to become familiar with both the strengths and weaknesses of each student. Often instructors build choreography based on the strengths of the dancers in the class, which offers a medium in which to showcase individuals' talents. This can provide people with different abilities with a sense of contribution to the choreography and dance class as well as have them acknowledged for their strengths and abilities, thus including and normalizing everyone in a group (Block, 2008). Another way that dance can normalize individuals' different abilities is having the same overall expectations for each dance student in a dance class.

Although the specific expectations in terms of technique might differ between students, having

the general expectations around aspects such as attendance, participation, and cooperation apply to everyone helps develop a sense of normalization and unity among the dance students (Block, 2008). Lastly, Block (2008) suggests dance performances can contribute to creating a sense of normalization among dancers by working with others towards a common performance goal.

In the past, ID was viewed from a biomedical perspective which viewed disability as something that should be cured or treated. Consequently, the disabled body largely remained invisible within society (Harmon, 2015). Similarly, dance is commonly viewed as best suited for people who are physically, emotionally, and intellectually able (Cone, 2015). New literature argues that dancing among people without disabilities offers individuals with disabilities an opportunity to inform how they are being viewed (Harmon, 2015). Furthermore, dance can provide people with a disability the opportunity to contribute to the shifting ways that both disability and dance is viewed (Cone, 2015; Harmon, 2015).

A final aspect of inclusion that the literature touches upon is the sense of belonging that dance provided individuals with ID. For instance, in her 2016 study which looked at the experiences of children with disabilities in elementary school dance education, Zitomer states "Children felt competent in their ability to participate, and generally valued the help they received from teachers, EAs, and peers. Their experiences in dance class appeared to contribute to children gaining a sense of belonging" (p. 228).

Although many researchers describe dance experiences as promoting inclusion and normalization for people with ID, other researchers explore the exclusion that exists within dance. One main aspect of exclusion within dance is the notion of being unfit to perform (Harmon, 2015).

Identity. The literature explores the ways that dance impacts the identity of people with disabilities. Dance allows individuals with different abilities to affirm themselves as beings who are entitled to respect, and complete access to rights and opportunities with unique abilities and talents, through the experiences of self-expression (Harmon, 2015). Furthermore, research highlights that dance is seen by some individuals with disabilities as a safe space which gives them the power of shaping their identity for themselves and others (Harmon, 2015). For example, in a recent study which explored dancers involved with an inclusive dance project, The InVisible Difference Project, dancers with physical disabilities describe their values about performing for others. One dancer stated, "I perform to take control back over how I am viewed. You have the opportunity, through dance, to shape how people see you" (Harmon, 2015, p. 494).

# **Factors of Dance Participation**

The literature explored various factors that relate to recreational dance participation among people with ID. Accessing dance opportunities and cultivating positive dance experiences among people with ID are highly discussed among research findings.

Accessing dance opportunities. Despite the increase of inclusive dance opportunities, one of the major barriers that the literature discusses is the lack of accessible dance opportunities for individuals with ID (Reinders et al., 2015). Aujla and Redding (2013) explain that one of the reasons for a lack of inclusive dance opportunities is based on narrow attitudes and expectations within dance communities about the constitution of dance and dancers. The same researchers also state that such perceptions are also influenced by the widespread idea that individuals with disabilities are only able to achieve limited success in dance. Another possible reason for the limited amount of inclusive dance opportunities is the lack of training for dance instructors to appropriately support individuals with disabilities (Aujla & Redding, 2013). Kaufmann (2002)

suggests that if dance instructors were more educated on supporting dance students with disabilities, dance would be more accessible for people with ID.

**Positive dance experiences.** One of the ways in which dance classes attempt to support the needs of students with disabilities is with dance instructor aides, who are usually assigned to assist specific students with the dance instruction. Although many people with ID find such instructor aides to be helpful in facilitating positive dance experiences, other individuals express that dance instructor aides can create barriers to positive dance experiences (Zitomer, 2016). In her study, Zitomer (2016) gathered data on the role of dance instructor aides. The findings reveal opinions toward the role and actions of the dance instructor aides to be widely in opposition. Many students were more engaged in the dance class with support of instructor aides or were disengaged without them. For example, one participant felt more comfortable knowing that someone who understood his needs could closely support him throughout the class. However, some students did not want to have instructor aides as the aides impeded with dance participation. For instance, Zitomer observed that one participant "moved more freely and authentically when the adult supporting him stepped aside and allowed his peers to support him. The absence of an intervening adult enables Aiden to move easily blend into the group" (2016, p. 225). Other examples describe the instructor aids as providing too much support that the student was unable to move creatively and naturally and thus disregarded the freedom, capabilities, and autonomy of the students. These findings indicate that the amount and type of support from instructor aides must be carefully determined for dance students with ID.

In addition to research discussing the role of instructor aides among dance students with ID, research also addresses the various attitudes and characteristics that might facilitate more positive dance experiences for people with ID. The literature explains the importance for dance

instructors of individuals with disabilities to possess specific qualities including being flexible, creative, and tolerant. When dance instructors possess such traits and skills, their dance students are better able to participate and enjoy their dance experiences (Cone, 2015). Other research suggests that dance instructors for people with disabilities must embrace peoples' different abilities and strive to create an environment of inclusion where every student is accepted and valued (Kaufmann, 2006). Furthermore, dance instructors should provide opportunities and encouragement for dance students to have positive dance experiences as well as possess a genuine belief in the potential of every student (Cone, 2015), unrelated to any predetermined assumptions on the dance abilities of people with disabilities (Goodwin, Krohn, & Kuhnle, 2004). Moreover, instructors should view different strengths and abilities of each student as an opportunity to create new choreography based on the students' natural movements (Cone, 2015).

The literature also discusses the need for instructors of dance students with ID to be informed and knowledgeable about specific things, such as their individual movement abilities, preferences, and strengths, to contribute to positive dance experiences for students to effectively accommodate, as necessary, and choreograph movements for each student (Block & Johnson, 2011). In addition, such dance instructors should be familiar with various communication methods and supports such as communication boards, task cards, visual aids, and mapping to support with communication and teaching choreography as needed. In addition, dance instructors should view any assistive devices as an extension of the dancer and could consider creatively using them in choreography based on the approval of the dancers (Block & Johnson, 2011). Furthermore, Block and Johnson (2011) indicate that dance instructors should be informed of the current emotional states of their students with ID to best support their students.

There is some research published on teaching methods for dance instructors of students with ID. For instance, Block and Johnson (2011) argue that such instructors should use individualized education programs (IEPs) to help identify learning objectives for individual students including social goals. They also suggest that when working with people with ID, dance instructors might need to consider teaching at a slow and gradual pace with more repetition and breakdown of instruction and movement, based on the students' cognitive abilities. In addition, Block and Johnson (2011) advise dance instructors working with individuals with ID to establish a regimented structure and schedule to the class and follow it each week as well as articulate cues for the students before transitioning to each activity. They explain that this will accommodate any potential need for routine and support during transitions. Furthermore, they argue that dance instructors must be aware and accommodate for the slower reaction time and difficulty with quick weight shifting and precise foot movements that some dancers with ID may experience. Lastly, they explain that encouraging dance students to mirror the movements of another dancer, a method referred to as paralleling or shadowing, might assist dance students with ID to learn choreography.

The research studies which look at individuals with ID and recreational dance in a community-based setting are limited and the need for further research has been expressed, especially with regard to the benefits of community dance programs for people with ID (Reinders et al., 2015).

### **Intellectual Disability Research Participation**

Before I engaged in qualitative research involving a participant with ID, it was crucial to explore the relationship between people with ID and qualitative research. Although there are many considerations that must be made when developing research involving people with ID,

individuals from this population are fully able to participate in research (Hall, 2013) and communicate their experiences (Abbott & McConkey, 2006). Historically, research practices exploited the vulnerability of this population as most of the research of this nature was physically harmful towards individuals with ID and was often carried out without consent (Freedman, 2001). As public attitudes towards individuals with ID began to shift, methods of protecting the vulnerability of this population were adopted by researchers and research ethic boards (Beh, 2002).

Even though individuals with ID have been significantly excluded from the research arena, there is a great need for including individuals with ID in this area to increase inclusion, health-equity, and shift social attitudes towards such individuals (McDonald & Raymaker, 2013). Furthermore, including people with ID provides such marginalized individuals with a voice. Exposing the perspectives of people with ID within research, policy, and practice will inform and advance the knowledge in this field (Swaine, Parish, Luken, & Atkins, 2011).

Understanding the thoughts and experiences of such individuals not only addresses and advocates for various issues that are important to individuals with ID (Pugach, 2001), but also can provide such individuals with the opportunity to feel a sense of value and purpose (Wilkenfeld, 2015). Intellectual disability research informed by people with ID can offer such individuals a sense of empowerment (Mactavish et al., 2000), self-determination (Tannous, Lehmann-Monck, Magoffin, Jackson, & Llewellyn, 1999), and control (Corby, Taggart, & Cousins, 2015). Other benefits of including people with ID in research are that it can provide a sense of enjoyment (Hall, 2015) and productivity for such participants (Wilkenfeld, 2015).

Not only does the data stress the need for including people with ID in research participation, but several studies advocate the need for inclusion specifically within qualitative

research (Cousins & Milner, 2007). The literature defends this correlation by explaining that qualitative research methods are conducive for developing rapport between researcher and participant (Taylor et al., 1995). Understanding this disenfranchised population through qualitative research is supported by the World Health Organization (WHO), which proposes that people with ID should be more involved in qualitative research studies (WHO, 2011).

# Conclusion

This chapter has outlined the literature on individuals with ID and their experiences with sense of self, leisure, therapeutic recreation, recreational dance, and research participation. This literature has informed the direction of my case study and provided me with a thorough understanding of the research that has previously been developed in the areas of intellectual disability, leisure, recreational dance, and sense of self. The following chapter will present the research methods I adopted to conduct this case study.

## **Chapter 3: Research Methodology and Methods**

Individuals with ID face specific barriers to developing a positive sense of self, in particular stigmatization and self-stigmatization. The fields of leisure studies and therapeutic recreation propose that leisure engagements can enhance sense of self. Thus, the focus of this case study was to explore the lived experiences of an individual with an ID with community-based recreational dance and any impact such experiences may have had on his sense of self.

This case study is framed in a qualitative research perspective. Qualitative research is defined as social research that explores the complex ways that people come to understand their thoughts and experiences (Savin-Baden & Major, 2013). Qualitative research is fundamentally subjective (Savin-Baden & Major, 2013). The data that I collected through this study is based on the unique interpretations and experiences of individuals with ID, which is in line with the subjective nature of qualitative research. Second, qualitative research acknowledges the complex realities that are unique to each individual (Savin-Baden & Major, 2013). Because the data from this case study is based on the perceptions and experiences of individuals, it is important that the research approach supports the varying narratives among individuals.

This chapter will present the various methods through which I conducted this case study. I have based my research decisions on the literature on phenomenological research, dance, and ethical research participation with individuals with ID. First, I will present the theoretical framework that guided this research. Then, I will explain the steps I took to collect and analyze the data. Lastly, I will present ethical considerations that helped guide this study.

#### **Theoretical Framework**

This study is guided by the principles of constructivism, hermeneutic phenomenology, and critical disability theory.

### Constructivism

Through this case study, I aimed to understand the experiences of individuals with ID with recreational dance, and how, if at all, these experiences affect the sense of self among such individuals. This exploration assumes that individuals construct their sense of self based on their past experiences and perceptions. As such, this study adopts a constructivist approach to research. Constructivists argue that individuals do not acquire nor discover knowledge, rather they construct knowledge and realities from personal experiences and perceptions (Lincoln & Guba, 1989; Lincoln & Guba, 2003). More specifically, it is the concepts, models, and schemas developed from personal experiences that inform the way individuals understand and construct meaning (Schwandt, 2000). Because of this process, knowledge and realities are intensely personal and complex (Lincoln & Guba, 1989; Lincoln & Guba, 2003).

Philosophically, constructivism centres between relativism and realism. Whereas it is relativist in that people create their reality relative to their own experiences, it is also realist as it can be argued that realities are construed based on things that exist externally to us and our sense of experience (Raskin, 2002). In other words, how we understand something will differ based on our experiences, however these different interpretations do not change the fact that things exist. For example, we see police cars on the road because they exist; whether we view them as safe or threatening is based on our past experiences.

Constructivists seek to understand how people construct knowledge and interpret such realities by consulting with individuals involved with the topic of particular research being conducted (Petit & Huault, 2008). Raskin (2009) explains that nobody can fully understand how a person experiences the world, except for that person. However, through communicating our

experiences, he asserts that we can come to understand, to an extent, how others construct their realities, and use our own constructed knowledge to assume what cannot be communicated.

As a constructivist researcher, I have sought to understand the realities of the participants for this study through communication and consultation. Furthermore, I believe that, like every individual, the participants construct their own realities and knowledge based on their past experiences and perceptions. Therefore, with this paradigm in mind, I acknowledge that the findings may not be generalizable, and each set of experiences are unique, complex, and richly personal. In addition, as a researcher with a constructivist lens, I have approached this study with my own personally constructed sense of reality, which has inextricably informed how I conducted this study and interpreted the data. Because my own experiences have impacted this study, it is important that I share some of my experiences and outlooks that have inevitably informed my decisions and interpretations as a researcher. This information has been discussed in the section called 'personal stance' at the beginning of chapter one. Through a constructivist lens, I came to this study with an understanding that we construct our own realities based on our past experiences and that much understanding can be gained by exploring such realities.

### **Hermeneutic Phenomenology**

Before I discuss hermeneutic phenomenology, it is important to explore the broader theoretical framework and methodology of phenomenology. Similar to constructivism, phenomenology is also based on the idea that realities are constructed by experiences and are therefore highly subjective and unique to the individual. Furthermore, like constructivists, phenomenologists aim to understand phenomena.

Encompassed within the broader theoretical perspective of interpretivism, phenomenology refers to "the systematic attempt to uncover and describe the structure, the

internal meaning of structures, of lived experience" (van Manen, 1990, p. 10). In other words, phenomenologists attempt to understand what it is like for an individual to experience a phenomenon. For instance, phenomenologists may want to understand what it is like to be a mother, to be a refugee in Canada, or to have a disability while entering the dating world. For this case study, as a phenomenologist, I sought to understand what it is like to have an ID and dance; I wanted to understand what this means as it relates to the way these individuals see themselves. Cohen, Kahn, and Steeves (2000) state that the research design should align with the question being asked. As previously mentioned, I sought to understand the experiences of someone with an ID with community-based recreational dance. This research interest is best addressed by directly asking an individual with an ID who is involved with this type of dance about their experiences and the meaning that such experiences provide. This data is best supported and enhanced by understanding the perspectives of individuals who are significant to this individual who understands his relationship with dance. These perspectives are based on the experiences and opinions of individuals, and according to phenomenologists, are therefore uniquely subjective.

Similar to constructivism, the founder of phenomenology, Edmund Husserl (1859-1938), argued that people and the way they experience the world should be examined as connected entities (Valle, King, & Halling, 1989). In this way, when phenomenologists attempt to understanding a phenomenon, they focus on learning *how* individuals experience that phenomenon, as opposed to researching about phenomena from an objective point of view. With this in mind, the information that I gathered for this research is rooted in the ways that the informants described their experiences either with dance and having an ID or their perspectives of the dancer and his relationship with dance. In this way, the findings reflect the subjective lived

experience of one dancer, and therefore the results are unique to this person, and potentially contain new insight into this phenomenon that the literature has not yet explored.

A significant characteristic of phenomenological research is bracketing researchers' biases. Osborne (1994) describes bracketing as identifying one's prior knowledge and preconceptions about the phenomenon being studied and then attempting to put them aside to learn about the phenomenon as it is lived by others. Although it can be argued that disregarding one's own ideas and opinions of a phenomenon is ultimately impossible, some researchers continue to put effort towards bracketing their biases to contribute to trustworthiness and transparency among research. For the purposes of this case study, I have outlined my relevant experiences and preconceptions in the section titled 'personal stance' at the beginning of chapter one.

There are several types of phenomenological research, including transcendental phenomenology, hermeneutic phenomenology, and phenomenography (Savin-Baden & Major, 2013). This research investigation employs a hermeneutic phenomenological approach, both theoretically and methodologically.

From the shadows of Husserl, Martin Heidegger (1889-1976) developed a slightly different philosophy. While Husserl focused on uncovering phenomena, Heidegger argued that there is more value in ascribing meaning to phenomena (Wilson & Hutchinson, 1991). For example, instead of simply examining the behaviors of someone with alcohol dependency, hermeneutic phenomenologists place more value in exploring what it means and how it feels to have an alcohol dependency. According to Kvale (1996), hermeneutics involves interpreting human culture as texts and examining such texts to find meaning. According to van Manen (1990) hermeneutic phenomenological research is concerned with interpreting lived experiences.

As such, this case study examines what it is like to have an ID and be involved with dance. In this way, I have considered the language, tone, and behavior of the informants from this case study to gain an understanding of what it means to dance while having an ID for this individual.

Hermeneutic phenomenology is built upon Heidegger's concept of 'dasein', described as 'being-in-the-world', which implies the need to consider intimately related factors and contexts of the individuals being questioned. For example, when attempting to understand the lived experiences of individuals, it is important to address significant factors related to their mind and body, as well as consider historical, social, and cultural contexts that may impact the individuals or phenomena being studied (Heidegger, 1962; Koch, 1995). Therefore, as a hermeneutic phenomenologist, I have considered important factors and contexts related to both the participants and phenomenon. Hermeneutic phenomenology has also been influenced by Hans-Georg Gadamer (1900-2002) who translated Heidegger's work into more practical application (Gadamer, 1976; Polkinghorne, 1983). Gadamer (1976) insisted that when conducting hermeneutic phenomenological studies, researchers must have a bond to the phenomena being investigated. In line with this position, having a connection to both individuals with ID and community-based recreational dance, I was able to ground this case study in perspective and understanding.

The interpretive process of hermeneutics is based on the 'hermeneutic circle', which describes the approach of moving back and forth between the parts of an experience to the whole of an experience (Polkinghorne, 1983). In other words, hermeneutic phenomenologists want to delve into understanding phenomena, and in doing so, must explore phenomena from different angles to achieve a rich understanding. As this theory suggests, I have approached the

phenomenon of dance among people with ID from various angles and perspectives to truly understand what it means to experience this phenomenon.

Furthermore, many dance researchers also have relied on hermeneutic phenomenology as a research methodology and theoretical perspective. For example, Reinders et al. (2015) believed hermeneutic phenomenology allowed them to understand their participants' lived experience of a dance program. In addition, in a 2015 study, Corby et al. indicate that hermeneutic phenomenological methodologies are specifically common and effective among studies which involve participants with ID as they represent participants' subjective thoughts and experiences while considering the researchers' stance. Similarly, based on the literature, the most common methodology used among intellectual disability research is hermeneutic phenomenology. Not only does hermeneutic phenomenology invite readers into the worlds of individuals with ID, but it also provides people with ID with a platform for their voices to be heard (Corby et al., 2015).

# **Critical Disability Theory**

Although the treatment of people with disabilities has shifted over the past few decades, it is well documented that people with disabilities, among other minorities, continue to experience marginalization, exclusion, and discrimination in North America today. Critical disability theory challenges disability ideologies introduced by liberalism and advocates for an approach that is more inclusive and involves an even distribution of power (Pothier & Devlin, 2006). Under a society driven by liberalism, the attitudes towards people with disabilities, both on a micro and macro level, are those of predominately either charity or welfarism. Valuing autonomy and independence, liberalism conceptualizes disability as misfortune. Disability has become hierarchical; being able-bodied is viewed more highly than being disabled. Although these approaches may be well-meaning, critical disability theorists argue that liberalism has

continued to manifest inequality for people with disabilities on various levels. Critical disability theory aims to create real participatory inclusion, which begins with a shift in the way disability is conceptualized (Pothier & Devlin, 2006).

Critical disability theorists acknowledge that language plays a role in the stigmatization and marginalization of people with disabilities. They argue that the term 'disability' has a negative connotation and polarizes people with and without disabilities, manifesting an 'us versus them' mentality. Disability is essentially neutral in value. Disability is not inherently good or bad; it is how humans define terminology and label others that dictate worth or value. Critical disability theorists work towards making the term 'disability' less pejorative and more neutral in value (Pothier & Devlin, 2006). For this case study, while I contemplated using a different term to describe disability, I concluded that the term 'disability' is the most appropriate terminology to use, although I acknowledge its pejorative tone.

With the current conceptualization of disability as misfortune, many methods of prevention, treatment, cure, and rehabilitation from disability are sought. Although treatment, cure, and rehabilitation can be helpful for people with disabilities, obsessions from people without disabilities over these goals can imply that having a disability means being 'defected' and in need of fixing (Pothier & Devlin, 2006). This is not to say that critical disability theory simply ignores disability and difference; rather it demands that difference be confronted when it is relevant for identifying inequality and exclusion and developing goals for full inclusion and participation without creating a hierarchy of difference. Critical disability theorists argue that disability is simply a socially constructed barrier, and it is the responsibility of the larger community to include all its members. It has been well researched that while people with disabilities experience limitations from their impairments, most of the barriers they experience

are due to society's unwillingness to learn and adapt (Pothier & Devlin, 2006). Further, research suggests that many people with disabilities, especially those with hidden disabilities, go to great lengths to attempt to downplay the significance of their disability or pass as someone without a disability, to protect oneself from stigmatization. In this way, the pressure is put on people with disabilities to accommodate to one's environment, when more responsibility should be placed on the environment to accommodate disability (Pothier & Devlin, 2006).

Critical disability theorists reject the approach that liberalism takes on citizenship and insists that societies reconsider parameters around citizenship. Critical disability theorists suggest that in Canada, citizenship is partly defined by productivity. In other words, people are considered citizens based on their potential for productivity (Pothier & Devlin, 2006). For some people with disabilities, this means that the socially constructed barriers they experience negatively impact their worthiness to be considered as a citizen. Critical disability theorists reject basing citizenship on productivity and cost-benefit analysis. They argue that we must be able to consider particular experiential circumstances when determining citizenship, and not simply define people based on their potential for production (Pothier & Devlin, 2006).

Priestley (1997) outlines six principles of engaging in critical disability research. First, the research should establish a commitment to adopting a social model of disability. This will involve a shift from viewing disability as impairment-related issues towards understanding the disabling physical and social barriers in our environment (Barnes & Mercer, 2010). Second, Priestley (1997) insists on surrendering prior ways of looking at disability from an objective political stance and rejecting the sentiment that researchers are neutral. Third, commit to producing research that will practically benefit and self-empower people with disabilities and/or remove disabling barriers identified as issues by people with disabilities. Fourth, placing more

control over the research in the hands of the participants with disabilities who are the first-hand experts in this area. Fifth, allow individuals to share their experiences with social issues and disabling barriers. Last, employ various data collection methods to gather a myriad of perspectives from people with disabilities (Priestley, 1997).

By adopting constructivism, hermeneutic phenomenology, and critical disability theory as my lens, I explored the dance experiences of one individual with an ID and developed a rich understanding of what it is like for this individual to dance. With these theoretic frameworks as my guide, I uncovered the dance-related experiences and thoughts of this individual and shed light on the ways that such experiences impact this person's sense of self.

#### **Research Methods**

### **Pilot Research**

The initial research plan for this study was to complete a pilot study with three participants with ID who participated in recreational dance. However, I did not receive enough data to complete that study effectively. I completed the data collection process with each of three participants, however was unable to obtain enough data from two of these individuals. Although the data was incomplete, it laid the foundation and informed key elements to shift this study to a case study of one participant. This case study, then, is based on the participant who provided me with enough data. Therefore, many of the research methods that were employed in the pilot study contributed to this case study.

### **Ethical Clearance**

Institutional review boards ensure that studies are conducted in an ethical manner. I applied to Brock University's Research and Ethics Board for both the pilot research and this case

study. My application was granted clearance on April 17, 2018 for the pilot study (file #17-351), and this case study on May 28, 2018 (file #17-389).

### **Site Selection**

With the goal of accessing individuals with ID who are involved in recreational dance, I researched integrated dance programs in Ontario, Canada. One of the few options was an integrated dance program operating in the Greater Toronto Area (GTA) in Ontario. Founded and operated by occupational therapists and dance instructors, this program is a community-based recreational dance program that "provides inclusive and accessible programming in dance studies" (Program Directors, 2017). The directors state that their program aspires to "create opportunities for individuals with additional needs to access community leisure activities...[and] enable full participation in dance and arts programming, in order to share the many benefits that they have experienced themselves through participation in the arts with others" (Program Directors, 2017). This company offers about 16 dance classes in various private host studios across the GTA for the full studio season (September to June), along with a few classes and day camps offered during the Summer. The dance classes are taught by dance instructors who are certified with the Canadian Dance Teachers' Association. The instructors also receive training and support from occupational therapists in a consultative fashion, which includes adaptation methods for the content and structure of the classes to meet the students' needs. Based on individual needs, many dancers will work one-to-one within the class with volunteers, who apply through the company and are trained and supported by occupational therapists.

There are several different types of classes offered to children, teenagers, and adults, and each class is 45 minutes in length and offered on a weekly basis. The classes focus on dance styles including, ballet, jazz, hip hop, and tap, and combine both instructional and

improvisational components. These classes focus on "teaching dancers to move in different ways and appreciate a multitude of music styles and quality" (Program Directors, 2017). These classes also offer dancers opportunities to learn technique as well as practice improvisation.

Dancers pay to register for each class. There are a few options for students to receive financial support; the company offers a few bursaries to selected applicants, which is funded by private donors and sponsors. Additionally, there are potential funding options through Ontario government programs such as Passport and Special Services at Home, as well as organizational and corporate funding options. I thought that this dance program might help me access eligible participants this research.

The dance classes vary depending on target age group of dancers and genre of the class. However, most of the dance classes focus on aspects of dance such as movement qualities, rhythmicity, body coordination, spatial awareness, and movement patterns. The classes incorporate both improvisation and choreographic work as well as solo and group work. The dance instructors address dance vocabulary, music quality and use props to support class facilitation. Through these classes, dancers develop skills such as genre-specific dance technique, balance and coordination, body and spatial awareness, musicality, and social skills. Typically, each class includes a warm up and provides opportunity to travel across the dance studio, practice dance skills in the centre of the studio, and play dance-related games such as freeze-dance. The classes are generally led by the instructor, although dancers are encouraged to demonstrate or lead exercises as well.

# **Gaining Entry**

For the pilot study, to gain support from the directors of the dance program, I e-mailed them a letter introducing myself, my study, and requested their assistance with recruitment for

my study (Appendix A). The directors were interested and generously willing to assist me with recruitment and provided me with a letter of approval in support of my research (Appendix B). The directors then contacted the dance studio owners and instructors who agreed to support me in my participant recruitment.

### **Sampling Procedures**

I used purposeful sampling strategies to select participants for this study. Not only are purposeful sampling strategies advocated by literature on qualitative research (Savin-Baden & Major, 2013), but many hermeneutic phenomenologists rely on purposeful sampling methods as well (Cohen, Kahn, & Steeves, 2000; Corby et al., 2015).

Researchers often seek the support of significant individuals, such as a staff member of potential recruitment sites, to identify individuals who meet the participation criteria (Corby et al., 2015). For the pilot research, I relied on the program directors and associated dance instructors for guidance on which participants might be eligible and interested in participation. The program directors were involved throughout the recruitment process. For the case study, I relied on the dancer's guardian for suggestions of potential participants.

Informed consent. One of the key issues that can create barriers around intellectual disability research relates to ethical concerns regarding the ability of people with ID to provide informed consent. As members of a vulnerable population, research suggests that people with ID are more likely to be acquiescent, complaisant, or lack assertive decision-making skills, and therefore may not question intrusion from researchers (Griffin & Balandin, 2004). Considering this concern, I began to involve the dancer in this case study upon receiving informed consent. In addition, I ensured that I had assent from this individual prior to and throughout the research process, by looking for signs of interest and engagement.

Content and process. There are various factors that must be addressed when attempting to inform potential participants with ID about a research study and obtain their consent for participation. For instance, Griffin and Balandin (2004) stress the importance of ensuring that potential participants have experience with decision-making or are provided with training in decision-making prior to being informed about the research. Additionally, Murphy and Cameron (2006) encourage researchers to gain knowledge about the comprehension and communication abilities of a potential participant. I consulted the dance program directors and the guardians of eligible and interested dancers about their decision-making skills and comprehension and communication preferences, which informed my communication styles with the dancers.

To obtain participants for the pilot study, the dance program directors sent an e-mail to the guardians of eligible dancers, which introduced me and my study, and informed them that I would be visiting their children's dance studio to discuss the study in person. In April and May 2018, I traveled to four regions across the GTA and visited 4 host dance studios and classes to recruit participants. During these visits, I introduced myself and the research to both dancers and any guardians who were present in the studio lobbies. I spoke with each class for approximately 10 minutes (Appendix C).

Individuals with ID are at a higher risk of coercion as some may lack the comprehension skills to fully understand participation proposal forms and the various roles and repercussions of participation (National Disability Authority, 2009). Because of this, I put forth significant effort to reduce the risk for coercion. As advocated by past studies involving participants with ID (Swaine et al., 2011), during the introductory sessions, I used comprehensible language and accessible vocabulary to introduce this study to the dancers as well as relied on images as visual aids to support comprehension (Appendix C). Along with considering language and visual aids, I

attempted to increase comprehension by encouraging the dancers to ask questions about my research and I answered any questions that were asked in a comprehensible fashion.

Furthermore, I ensured that the dance instructor was present when I introduced the research study to the dancers, which researchers say allows potential participants to address questions and concerns to such individuals as well as reduce the risk of coercion (Murphy & Cameron, 2006).

During my visits to the dance classes, each interested dancer and his/her guardian were given a written letter of invitation: one created for the dancer and another for the guardian (Appendix D & E). During the remainder of these dance classes, I spoke with some of the guardians of eligible dancers who were in the lobbies and introduced the study to them and inquired about their willingness to have their child participate in the study. Interested guardians were provided written letters of invitation. Once both the guardian and dancer expressed interest, they were each given an informed consent form (Appendices F & G). The program directors sent an e-mail to parents of eligible dancers who expressed interest in participating the research study and were not present at the dance studio. Letters of invitations were attached to these e-mails. Lastly, with permission from the directors of the dance program, I put up posters with basic information on my study at their various host dance studios (Appendix H).

As mentioned in section 'Pilot Research', I received consent from three dancers and their guardians. I completed the data collection process with each participant, although I did not receive enough data from all three participants. I did, however, receive a sufficient amount of information from one participant. Therefore, I decided to conduct this case study, which would use the data I gained from this individual, as well as collect data from three other individuals who are in this dancer's life. Once I received ethical clearance for the case study, I sent an e-mail to the guardian of the participant inquiring if she and her child would be interested in

participating in a case study centred around her child. After the dancer and guardian expressed their interest, I sent the guardian a more formal written letter of invitation and informed consent form, which included her participation in the study and her consent to have the case study be conducted based on her child (Appendices I & J). Similarly, I received verbal consent from the dancer for his involvement in this case study (Appendix K). Once I received written consent from the guardian for her participation and approval of the study, she suggested two other individuals in her child's life who might be able to provide rich data. I received their e-mail addresses and sent each individual a written letter of invitation and informed consent form (Appendix L & M). Each potential participant was informed that he or she would receive a Tim Horton's gift card, valued at 25 dollars, upon agreeing to participate in my research as a token of my appreciation for their commitment.

Consent providers. When conducting research with individuals with ID, determining who is able to provide informed consent is an important factor to consider. Dalton and McVilly (2004) recommend "that an adult person with intellectual disability should be assumed capable of providing informed consent, unless it has been established otherwise; for example, by formal assessment and/or legal determination" (p. 62). For individuals with ID who have been determined to be incapable of providing consent, Griffin and Balandin (2004) argue the need to obtain proxy consent, which they define as consent from an advocate on behalf of the individual with ID, such as a legal guardian. When obtaining proxy consent, Wilkenfeld (2015) suggests informing the guardians of the research study in-person if possible, as opposed to over the phone. Research argues that when a proxy provides consent on behalf of an individual to participate in a research, the participant should provide assent as well (Griffin & Balandin, 2004). However, if assent has been given by a potential participant and proxy consent has not been provided,

Freedman (2001) advocates that having a discussion between the potential participant and proxy should be considered. As suggested by past research, I obtained written consent from both the dancer and his guardian for his participation.

Ethical considerations. It is important for researchers to understand that consent provided by either the participants or a proxy as well as assent from the participant can be withdrawn at any time and may be expressed in various ways without the need for justification or penalty of any kind (Griffin & Balandin, 2004). As suggested by the literature on research conducted with participants with ID (Hall 2013; Jones, 2007; Murphy & Cameron, 2006), I have treated consent as an ongoing process throughout the duration of this case study. As recommended by the research, I periodically 'checked in' with the participant regarding his thoughts and feelings towards participation.

## **Participant Selection**

Qualitative research studies that include involvement from people with ID often recruit participants with specific criteria. For example, a meta-analysis of 28 phenomenological studies with research participants with ID, all the participants had sufficient verbal skills to describe their experiences and most of the studies specifically noted that their participants had mild or moderate ID (Corby et al., 2015). In accordance with previous research involving participation from people with ID, inclusion guidelines for my study required the dancer to have a diagnosed mild or moderate intellectual disability, to be able to communicate verbally, and be 18 years of age or older. Furthermore, participation in this research required the dancer to be enrolled and regularly participate in a recreational dance class, as well as to have attended a minimum of four dance classes prior to the start of his participation in my research.

The number of participants for this study was based on phenomenological research standards and the size and guidelines of this case study. As supported by the literature on phenomenology and research involving individuals with ID, I recruited four participants for this study: one dancer and three supportive participants. Initially, it was my hope to only collect data from the dancers without input from others. However, I received a limited amount of data from these individuals and thus decided to involve significant others to enhance the findings. The participants in this case study include Miller, on whom this research is based, Jody, Miller's mother; Kate, Miller's dance instructor; and Gail, Miller's supervisor and family friend.

### Miller

This research is centred around a young dancer to whom I refer as Miller. Miller is a 22-year-old Caucasian male who lives with his family in a small town in Ontario, Canada. Among many things, Miller is extremely outgoing, confident, talented, and ambitious. He loves life and has an infectious sense of humour. His charismatic and kind-hearted nature makes him well-loved among his family, friends, and community. Miller is just over 5 feet and has dark blonde, straight, short hair. He wears glasses and often dresses in comfortable and casual clothing. He has Down syndrome. Along with Down syndrome, he also experienced a frontal lobe traumatic brain injury at age seven, which caused him to lose significant skills he had prior to the injury and altered aspects of his personality as well.

After graduating from high school, Miller has worked and volunteered in several positions involving work with others and manual labour, such as cleaning. He also attends an adult day program for individuals with developmental disabilities on a part-time basis. Miller does many things independently; however, he often works with an individual who accompanies

him to various engagements, who is referred to as his worker. Miller is involved with several leisure pursuits, one of which is dance.

Dance involvement. Miller has been taking dance lessons for four years at the local dance studio which offers integrated dance classes, which is part of a larger integrated dance program as outlined in the previous chapter. In addition, Miller also volunteers as a chaperone in the community youth dances for children. His role as a chaperone involves walking around the arena to ensure that the children are safe and happy, such as ensuring they are not using their cell phones in the room. Miller also is responsible for notifying his supervisor of any problems, for instance spilled drinks. In the past, Miller volunteered at the youth dances accompanied by his worker, however he has recently volunteered independently. While he volunteers, he also dances at his leisure, either independently or with the children. Miller sometimes attends various community social dances. He attends an annual dance-based social for a Down syndrome group to which he belongs. Throughout high school, he also was involved with a program that connects students with disabilities to students without disabilities, through which he attended several community dances. Additionally, Miller attends various sports banquets, which involve social dancing.

Through this dance program, Miller was enrolled in two different dance classes: tap and hip hop. Both classes were taught by a Certified Dance Instructor who owns the dance studio and has experience working with individuals with developmental disabilities in the community. Both dance classes incorporate a group performance in a dance recital at the end of the dance season for family and friends of the dancers.

Both classes focus on developing dance skills that are related to both tap and hip hop.

The classes focus on various dance elements including energetic quality of movements,

movement patterns, and choreographic structure. They also incorporate more fundamental dancerelated skills, such as body awareness, spatial awareness, energetic quality of movements, floor pathways, and rhythm. Each class involves learning various dance steps specific to its respective dance genre.

Tap class begins at the barre with the instructor leading a warm up of the body using basic tap movements, such as toe-taps, shuffles, shuffle hops, and ball changes. During this time, the instructor focuses on isolating various parts of the foot in movement patterns that involve very small and quick energetic qualities. After the warm up, the instructor leads the dancers in groups in locomotive movement patterns across the dance floor. Each week, the instructor focuses on similar movement patterns, and often building on the patterns from the previous week in accumulation, focusing on rhythmic skills. The dancers then meet in the centre of the dance studio and either create a movement combination incorporating the dance steps previously practiced across the floor or learn a piece of choreography. During the second half of the dance season, the class will typically work on their performance piece for the end-of-season recital. For this, the instructor does a brief verbal review of the combination, reviews the dance without music, and then incorporates music into the review.

Similar to the tap class, the hip hop instructor leads the dancers in a warm-up in the centre of the dance studio, starting with warming up the neck and working their way down the body. The warm up focuses on body isolations and increasing the heart-rate through various movement combinations involving hip hop steps such as the two-step, rebounds, and top rocks. Then, the instructor will lead the dancers through various movement sequences incorporating hip-hop steps, most of which were introduced in the warm up, focusing on directional awareness and tempo. Following this, the class travels across the dance floor in groups, focusing on

locomoting with the dance steps previously practiced. At this point, the dancers return to the centre of the studio and either learn a dance combination or practice their performance piece for the end-of-season dance recital. After the class is dismissed, a few of the dancers usually stay to work on improvised movements.

In addition to the dance classes, the participants also discuss other community-based dance-related pursuits in which Miller is involved. Miller volunteers as a chaperone at a monthly community dance for youth. These dances are geared towards youth between the ages of eight and 14. They are organized and hosted by community volunteers and take place in a hall in a memorial arena, with a stage, and typically have about 200 attendees. Hired disc jockeys play popular 'Top 40' music and the children dance freely. Typically, children dance in groups with their friends, however there is occasionally a few couples dancing in pairs during slow songs. The dances are supervised by volunteer chaperones, one of whom is Miller.

Lastly, Miller also occasionally attends a few different dance-based socials or community events where there is opportunity to dance freely in a social manner. For example, Miller attends an annual social, which is geared towards individuals with Down syndrome. He also attends various sports-related banquets that involved social dancing as a component.

### **Supporting Participants**

**Jody.** Jody is Miller's mother. She is a loving and devoted mother, who puts Miller's best interest before that of her own. She is extremely proud of Miller and is a constant support in his life. She is a strong advocate against stigmatization and works to increase social inclusion of her son and others with disabilities. She actively supports Miller's full participation in life, including full-time employment and romantic relationships, and values developing his independence and

social network. Jody and Miller's relationship is one with mutual respect and a close bond. They have a fun banter between them and a shared sense of humour.

**Kate.** Kate is Miller's dance instructor. She has been teaching Miller for four years. She has several years of experience working with individuals with developmental disabilities on a full-time basis. She is a dedicated dance instructor and has a positive relationship with Miller. Her connection with Miller is also one with mutual respect and admiration, trust, and a sense of humour.

Gail. Gail is a community-member who has known Miller and his family for many years. She organizes and supports the volunteer chaperones at the monthly community youth dances, at which Miller volunteers. Gail is also Miller's employer and supervisor for a casual job of cleaning a community space. Having watched Miller grow and mature, Gail has a significant affinity for him and greatly admires him and his development.

### **Data Collection**

To gain an understanding of Miller and his experiences with dance, I conducted interviews with the participants. According to Savin-Baden and Major (2013), an interview is "a conversation between two individuals in which the interviewer asks questions and the interviewee responds" (p. 357). Interviews are the primary method of data collection in hermeneutic phenomenological research. Interviews allow researchers to understand the lived experiences of others as well as explore the meaning that those experiences hold (Cohen, Kahn, & Steeves, 2000; Seidman, 2013).

Interviews are the main type of data collection methods used in research studies on dance and individuals with ID. Although there are exceptional factors that researchers must consider

when conducting interviews with participants with ID, the literature concludes that it is possible to conduct successful and effective interviews with such participants (Perry, 2004).

Interview characteristics. The interview questions inquired about Miller's dance-related experiences, his sense of self, and how, if at all, his dance experiences impact his sense of self (Appendix N). The responses from the interview with Miller informed the questions that I asked the other respondents. Additionally, the interview questions were also partly guided by the multidimensional approach to sense of self, proposed by Shavelson et al. (1976). Based on this model, I focused on inquiring about the social sense of self, involving peers and significant others, and the emotional sense of self, which includes emotional states, and the physical sense of self (Shavelson et al., 1976).

I conducted one interview with each informant throughout May and June 2018. Each interview was face-to-face and 40 to 60 minutes in length. Jody was present and contributed when needed during Miller's interview and Miller was present and contributed when desired during Jody's interview. All other interviews were one-to-one. My interviews with Miller and Kate took place in the dance studio, my interview with Jody took place in her home, and my interview with Gail took place in a local community centre. Each interview took place in a quiet space with either a window to the outside or a door to other populated spaces to protect those involved. The interviews were audio recorded using a digital recorder and transcribed by a professional transcriptionist, which allowed me to easily revisit and analyze the data.

The interviews were a combination of unstructured and semi-structured formats. As supported by hermeneutic phenomenology, combining these two types of interview styles creates some structure to ensure researchers obtain data that is specific to the area of focus; however conversational enough to encourage participants to introduce thoughts that may elicit important

revelations (Cohen, Kahn, & Steeves, 2000). In other words, employing conversational and interactive interviews allowed me to collect specific information from the participants as well as provide me with narrative data, which provides the possibility of exploring data that may not have otherwise surfaced. In addition, the interview questions were retrospective in nature, which asks informants to turn to their experiences of a phenomenon and directly talk about it. With retrospective interviews, broad questions about participants' experiences and perspectives on a phenomenon are usually asked at the beginning of interviews. Follow-up questions are then asked until the experience is completely described (Cohen, Kahn, & Steeves, 2000). Lastly, similar to past phenomenological research conducted with people with ID (Corby et al., 2015), interview questions primarily consisted of open-ended questions to gather rich data.

Along with verbal conversations, researchers who have interviewed individuals with ID on their dance experiences have incorporated the use of visual art to gather data. For example, Zitomer's research (2016), asked her participants to create art work, typically through the form of drawing, that depicted their emotions and experiences. Zitomer followed up the drawing with a discussion around the artwork to attribute possible meaning to the drawings. The same study also employed the use of images taken from the Microsoft Word clip art to facilitate, stimulate, and enrich the participants' responses. These images were preselected by the researcher based on her observations during her fieldwork (Zitomer, 2016). Similar to previous studies, during Miller's interview, I provided him with the opportunity to visually express his experiences and emotions related to dance in a drawing. I provided Miller with paper and markers and invited him to create a drawing that reflects his experiences with dance. After Miller agreed to this and completed his drawing, we had a brief discussion based on his artwork to gain a more accurate understanding of his creations and how it pertains to his experiences with dance.

**Interviewing Miller.** When collecting qualitative data from individuals with ID, there are several issues that researchers must consider. Most of these considerations are related to the communication and/or cognitive abilities of some people with ID (Corby et al., 2015; Jones, 2007). It is common for individuals with ID to experience limitation with comprehension and memory, which could make it difficult to address subjective phenomena and abstract concepts. Employing appropriate accommodations and strategies can support "practices of appropriate inclusion in research for adults with intellectual disability, so that ensuing knowledge is relevant to them and scientific literature more complete" (McDonald, Keys, & Henry, 2008). In other words, it is important to explore various strategies to accommodate the communication abilities and preferences of each participant. As advised by past researchers, I adapted Miller's interview to accommodate his communication style and comprehension skills in several ways. I spent approximately 20 minutes in total casually talking with Miller prior to his interview to develop a basic understanding of Miller's communication and comprehension skills. Similarly, I also observed the communication style between the dance instructor, Miller's peers in his dance class, and Miller's mother and tried to communicate with Miller is a way that complimented these approaches.

During my communication with Miller, I used simple language and spoke in a clear manner. Furthermore, I rephrased questions when necessary, simplified abstract concepts into more basic language, and used examples as needed to support comprehension. Because I was always communicating with Miller in the presence of either his dance instructor or mother, I also had the support of these individuals to aid in our communication and comprehension. Moreover, before my interview with Miller, with consent from everyone involved, I had taken photographs

of Miller dancing in his hip hop class. I developed these pictures and showed them to him to aid in his recall ability and encourage rich responses.

Lastly, researchers assert the need to be mindful of nonverbal cues regarding consent from research participants with ID. Non-verbal cues from the participants, such as arriving late to interviews, cutting interviews short, distractibility (Wilkenfeld, 2015), fatigue, or discomfort, may indicate that a participant is unwilling or unable to continue their interview and/or research participation (Hall, 2013). As recommended by this research, not only did I look for non-verbal cues, but I was also continuously 'checking in' with each respondent to ensure they were still comfortable and interested in continuing the interview.

### **Data Analysis**

Within hermeneutic phenomenological research, the goal of data analysis is to develop "a thick description that accurately captures and communicates the meaning of the lived experiences of the informants being studied" (Cohen, Kahn, & Steeves, 2000, p. 72). For this case study, I analysed the responses of the participants from which I created a set of findings that accurately describe Miller's experiences with dance. Consistent with hermeneutic phenomenology, I considered the historical, social, and cultural context of both the participants and related phenomena. Further, I have approached data analysis with the 'hermeneutic circle' (Polkinghorne, 1983) in mind, having gone back and fourth between specific responses and the whole of the data, ensuring that I developed a rich and full description of what it is like to experience dance for someone with an ID.

I took several steps towards the preliminary analysis of the data. First, I had the interviews transcribed by a professional transcriptionist. Next, as supported by hermeneutic phenomenologists, I read and re-read the text for initial interpretations, looking for essential

characteristics, a phase in phenomenology often called 'immersing oneself in the data' (Cohen, Kahn, & Steeves, 2000). Once I gained an understanding of the data, I analysed the data using the phenomenological method of thematic analysis. According to van Manen (1990), thematic analysis refers to "the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work" (p. 78). In practical terms, thematic analysis involves reading the text line-by-line, and phrases within the data are labeled with possible themes (Cohen, Kahn, & Steeves, 2000). I used thematic analysis not only because hermeneutic phenomenologists advocate its use (Cohen, Kahn, & Steeves, 2000; van Manen, 1990), but it is also a commonly used data analysis method in studies that explore the dance experiences of people with ID. For instance, Zitomer (2016) argues that thematic analysis in studies involving dance and individuals with ID supports drawing out rich data with which to develop complex accounts of the lived experiences of dancers with ID.

The next phase involved coding the data, which is "a system of symbols (such as letters or short words) that is used to represent and label a theme" (Savin-Baden & Major, 2013, p. 422). Coding reduces the data to a more manageable state as well as capture the meaning of the different components (Savin-Baden & Major, 2013). I coded the data using colours to highlight the text in two steps. After determining potential themes, I highlighted the text in several colours; each colour represented a different theme. Next, I coded the data in broader terms and overall perspectives (Appendix O). Once the data was colour-coded into themes, I read through the data and assigned each line of concept a descriptive word using coloured sticky-notes, which correlated with the highlight colour. These descriptive words formed the sub themes to the main highlighted themes.

After I employed thematic analysis, I interpreted the data based on the literature and my own understanding of people with ID, leisure, recreation dance, and sense of self. In hermeneutic phenomenology, data interpretation involves writing and re-writing. During this reflective process, understandings of the data was summarized, and a coherent picture of the phenomenon being studied took shape. Finally, I disseminated the findings in this written report.

The data analysis and discussion occurred over two major steps. All the themes are presented in chapter four. There were five major themes that permeated the data and those are acknowledged and further explored in chapter five.

### **Trustworthiness**

Because the nature of phenomenological research relies heavily on subjective accounts, it is possible for findings to misrepresent the true experiences of participants. To reduce this risk and to increase the level of trustworthiness, researchers must ensure that their findings are reliable, accurate, and trustworthy. One of the goals of hermeneutic phenomenologists is to produce findings that accurately reflect the dialogue that took place between the researcher and participants and reduce, as much as possible, the biases that the researcher brings to the study. In other words, their aim is to report data as it appears, rather than how the researcher would want it to appear (Cohen, Kahn, & Steeves, 2001). Complimentary to phenomenological practices, in order to achieve trustworthiness throughout this study, I have employed the methods of bracketing my biases and member checking the findings.

Osborne (1994) describes bracketing as identifying one's prior knowledge and preconceptions about the phenomenon being studied and then attempting to put them aside to learn about the phenomenon as it is lived by others. Although some researchers argue that bracketing will not necessarily provide the researcher with a clear view of a subject, bracketing

continues to be done among phenomenological studies (Cohen, Kahn, & Steeves, 2000). In a practical sense, bracketing involves researchers considering and recording in written form the assumptions and beliefs about the phenomena under investigation. This record serves as a reference point during the data analysis process (Cohen, Kahn, & Steeves, 2000). Before I began conducting this research, I bracketed my prior experiences and preconceptions regarding recreational dance and individuals with ID in the introduction of this written report in the section called 'Personal Stance'. In general, my biases include having a therapeutic recreation lens, experience with working with individuals with developmental disabilities, and being passionate about and benefiting from dance experiences.

Along with bracketing my biases, I employed the strategy of member checking, which involves reviewing the findings with the participants of the study to confirm that the research conclusions are congruent with the experiences of the participants (Savin-Baden & Major, 2013). For this case study, after I analyzed and interpreted the results, I spoke with the participants through e-mail, over the phone, and/or in person and received their confirmation that the results accurately represented their experiences and perceptions. This allowed the findings to be 'checked' by the informants and thus created a more trustworthy study.

Trustworthiness and participants with ID. There are several ways that research findings can be influenced from biases from informants, including those with ID. Perry (2004) indicates that there can be significant bias in the responses of participants with ID. Individuals with ID may respond to questions positively simply to appear agreeable to the researcher. There may also be bias towards responding negatively to questions involving socially undesirable behavior to deny association with such taboos. To reduce participant bias, I explained to Miller that there are no 'right' or 'wrong' answers, and that his responses will not impact anything in

his life or have any repercussions outside of himself (with the possible exception of abuse being disclosed). Moreover, having spent some time with Miller prior to his participation may have increased his comfort level and may have ultimately resulted in more accurate responses.

Another type of response bias that may be prevalent among people with ID is recency bias, whereby participants may likely choose the second of two parallel options (Perry, 2004). To avoid recency bias, I asked questions several times in different ways in an effort to yield more accurate responses. Furthermore, I simplified broader and more abstract concepts and questions and mainly asked open-ended questions, which hopefully reduced recency bias.

Lastly, due to the vulnerability of participants with ID, Iacono (2006) explains that there is a greater risk for researchers to make participation-related decisions on behalf of participants. Not only would this exploit and control the participants, but it could alter the research data as well. To avoid making decisions on behalf of the participants, I ensured that there was always Miller's mother present, with consent from all parties involved, to ensure that the content I recorded was consistent with the information and behavior from each participant.

### **Ethical Considerations**

In order to avoid conducting harmful and unethical research with participants, qualitative researchers must employ research accommodations, strategies, and rigorous ethical safeguards (Cohen, Kahn, & Steeves, 2000).

All physical data is being stored in a drawer of my locked private office and will remain there for six months following this study's completion, after which it will be shredded.

Additionally, all data on technological devices will be stored on password protected devices and destroyed after six months following this study's completion.

The literature stresses the importance of ensuring confidentiality throughout the research process based on the consent of the participants. If confidentiality and anonymity are promised, no identifying data should be elicited (Griffin & Balandin, 2004). As such, I sought to establish confidentiality through avoiding use of participant identifiers, such as participant names, throughout the study. As advised by Griffin and Balandin (2004), I assigned a pseudonym to each participant and omitted identifying demographic details.

Ethical considerations and participants with ID. According to the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID), research involving individuals with ID should maximize benefits and minimize risks as well as respect the autonomy and self-determination of each participant (Dalton & McVilly, 2004).

Risk of harm. The literature suggests that intellectual disability research increases the participants' risk for manipulation (Forster, 2011), abuse, victimization, and exploitation (McDonald & Raymaker, 2013). According to the IASSID, there is often a power imbalance between researchers and participants with ID throughout the research process (Dalton & McVilly, 2004). Most of this power balance stems from clashing demands from participants as well as academic research requirements (Griffin & Balandin, 2004). For instance, Wilkenfeld (2015) explains that various kinds of maltreatment can occur during the interview process, whereby the researcher's position of power may provoke the participants to continue their involvement when they potentially would rather cease their participation. Considering the risks for participants with ID, I have taken several steps to reduce and/or avoid harm. In efforts to keep informed consent an ongoing process throughout the research study, as previously discussed, not only was I mindful of non-verbal cues of Miller, which may have communicated a desire to either temporarily or permanently end their participation, but I also continuously

'checked-in' with him and periodically reminded him of his options to take a break or end the interview.

**Building positive relationships.** In addition to simply treating participants with ID respectfully (McDonald & Raymaker, 2013), researchers who work with participants with ID stress the importance of building a strong and positive relationship with each participant, which are characteristics I maintained while engaging with the participants. The literature indicates that by building rapport with their participants, it is critical that researchers ensure that trust and comfort are established (Taylor et al., 1995). Furthermore, the literature encourages researchers to spend time observing and interacting with the participants to gain their trust (Wilkenfeld, 2015) and an understanding of their personalities and communication preferences (Corby et al., 2015). However, other researchers suggest caution with this approach as it can also increase the risk of participants responding in order to please the interviewer (Corby et al., 2015). To reduce the power imbalance as well as develop trust and familiarity with the participants and myself, I spent some time in the dance class prior to the data collection process. However, I only spent a limited amount of time with Miller prior to his participation in the study to reduce the risk of biased responses to please the interviewer. Along with building relationships founded on trust, support, and respect, I tried to appear approachable and non-threatening by dressing in casual dance attire and acting in a casual and friendly manner.

Another risk of the researcher participant relationship is that false expectations of continuing the relationship with the researcher following the research study can exist, which can leave participants with negative feelings towards themselves and their interaction with the researcher. In order to minimize this risk, researchers must be clear and realistic about continuing friendships with participants (Griffin & Balandin, 2004). I expressed the risk of him possibly

wanting to continue a friendship with me and conveyed the reality that this will not be possible. Furthermore, I conducted myself in a manner that was not overly affectionate. Lastly, during the interview process, it is possible for participants to experience anxiety or distress for various reasons including interview content (Perry, 2004). Perry (2004) explains that researchers must have strategies for dealing with such anxiety or distress such as steering the dialogue away from distressing subjects or arranging post-interview support if any distress persists. To protect my participants, I provided the participants with information on support services for anxiety or stress that may have arisen after the research study was complete.

### Conclusion

This chapter has articulated the theoretic framework that guided my research. It has also outlined the steps I took to collect and analyze the data. Finally, it has presented the safeguards that were followed to ensure this study is trustworthy and was executed ethically. I believe that these research methodology and methods have allowed me to effectively and ethically conduct this case study and ultimately have helped me gather reliable and accurate results.

## **Chapter 4: Results**

This chapter will describe Miller's experiences with community-based recreational dance. This chapter will also present the ways that recreational dance impacts Miller as it relates to his sense of self.

Miller loves to dance and takes every opportunity to do so, whether it be in dance classes, socials, at sports games, or at his house. In the interview with Jody, she stated:

It doesn't matter where he is. He's always dancing...If he's in a movie, obviously he'll sit and watch a movie, but if he's in a different situation and music is involved, he's dancing...He will spend—like, he's not usually out here sitting with me. He'll be in his room, headphones on, guitar, and dancing, dancing and singing. It's like that's his world.

Dance is a source of much enjoyment for Miller. In the interview with Miller, he stated that dancing "feels good" and that "dancing make[s] me happy." He also really enjoys his dance classes and takes them quite seriously. When asked how he feels on his way to dance class, he said he feels "a little happy and [a] little excited." He does not like to miss his dance classes and prepares his dance bag the night before his classes in anticipation.

Miller's experiences with dance can be categorized into three major themes: connection, strengths, and personal growth. The section on personal growth will focus on explaining the ways that recreational dance impacts Miller's sense of self.

The following is a diagram of the results from this research (Figure 1). As indicated by this diagram, this study explored Miller's 'identity in motion' through understanding his dance experiences and sense of self, and how both phenomena relate to each other. Miller's experiences with recreational dance were positive, mainly due to the person-activity fit that was established between Miller's strengths, abilities, and interests and dance. In other words, for Miller, dance is

an authentic leisure pursuit. It is through this establishment of a person-activity fit that dance can offer Miller positive experiences and build his sense of self. If dance would not be an authentic leisure pursuit for Miller, dance would likely not impact his sense of self as positively as it does.

There were several significant themes within the data. The three themes that came from examining Miller's experiences with dance are connection, strengths, and personal growth, shown on the left side of the diagram in Figure 1. Each of these themes have sub-themes, which will be outlined later in this chapter. The three themes that inform Miller's sense of self are confidence, social feedback, and barriers and stigmatization, shown on the right side of the diagram in Figure 1. Collectively, these six themes from Miller's dance experiences and sense of self represent the data from this study.

Upon further reflection on the data from this research, there are five major themes that are most significant across this research that weave together both Miller's experiences with dance and his sense of self. These five major themes are strengths, relationships, belonging, confidence, and sexual energy as shown at the bottom of the diagram in Figure 1. Miller experiences these five themes as a result of the person-activity fit that is established between dance and Miller's values, interest, and strengths, which help inform his 'identity in motion'. These five themes will be discussed in the final chapter.

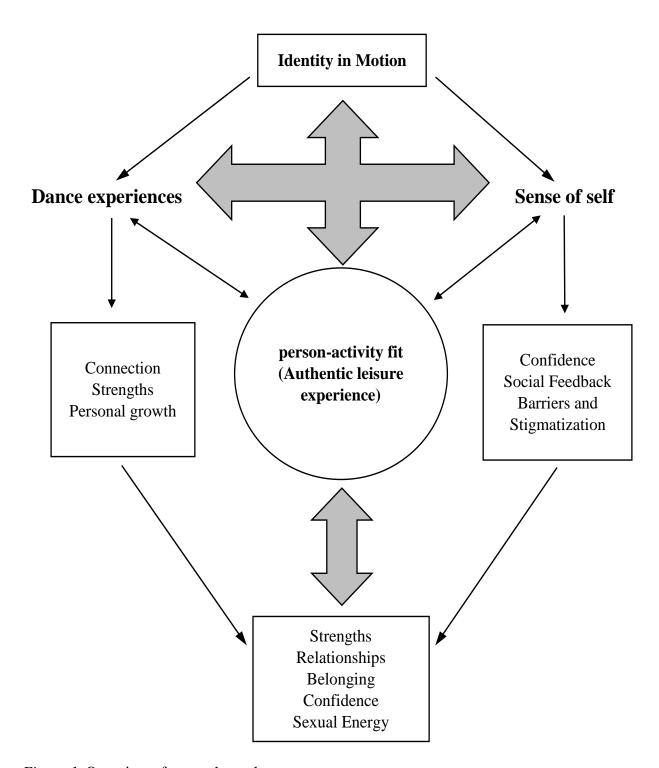


Figure 1. Overview of research results.

The following are two more detailed diagrams that outline the data from this study. These diagrams present the themes and sub-themes from the research results that will be outlined in this chapter. The first diagram (Figure 2) presents Miller's experiences with recreational dance. The second diagram (Figure 3) depicts the impact of recreational dance on Miller's sense of self.

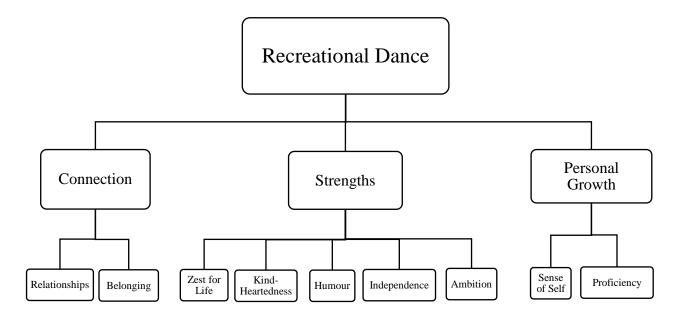


Figure 2. Results from primary research question.

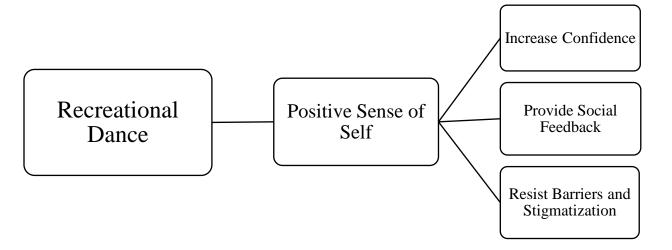


Figure 3. Results from secondary research question.

#### Connection

One of the major aspects of Miller's experiences with dance is social connection. Not only do recreational dance engagements offer a context for Miller to develop relationships, but they also allow him to be involved in his community. Overall, dance-related activities offer Miller opportunities to exercise his outgoing and extremely social nature. When I came into his dance studio the first time, he was the first person to approach me and introduce himself, which was very reflective of his friendly nature. Jody described Miller's extroversion saying, "He loves to meet new people...So wherever he goes he introduces himself...and then he'll introduce me and everyone else who's with him. So he's very, very social and outgoing. And you know, he speaks for himself, which is good." Moreover, his dance instructor, Kate, described Miller when she stated, "Yeah, no qualms, he'll go right over to you and be like, 'Hey, who are you? Why are you here? Nice to meet you', that sort of thing."

One of the major beneficial aspects of dance pursuits for Miller are the opportunities to create social connections. Jody, when asked about the benefits of dance for her son, she replied:

The social, because he gets to meet more people...he's in the older group, people his age, his peers. So that's important for me, is continuing with that, being out of high school now, keeping that social open. Because he is so sociable. So dance is good for that.

### Relationships – "[Dance] encourages [him] to be more social"

Dance-related activities allow Miller to form new friendships and foster other friendships he has from his non-dance world. Furthermore, dance opportunities provide Miller with a platform to meet new potential romantic interests. In addition, recreational dance pursuits offer Miller role-models to look up to, including his dance instructor, and as well allow him to be a role-model for others.

Friendships – "[At dance, we] chat all the time [and] fool around". Dance engagements provide Miller with the opportunity to build friendships with others. Miller stated that he likes to see all his friends from dance class, greeting them with high fives and hugs when he sees them at first, and they "chat all the time." When asked how he felt when he saw his dance class friends, he indicated that he felt really good. Miller also noted that his dance class friends and he like to be silly and "fool around" with each other, listing a couple of his close friends from dance class with whom he likes to be silly and playful. Furthermore, when asked why he looked so happy in a photograph of him dancing in class, he responded, "It make[s] me [happy] because my friend was cheer[ing] me up."

All the respondents described dance as providing Miller with a context in which to build friendships with others. Kate described dance as being "[a] common enjoyment, and then they build that little community." Both Jody and Kate mentioned the value for Miller of having male friends who are also involved with dance activities. Kate described the importance of male friends in the dance classes. She said:

Historically, over the years, Miller brings a lot of people with him to try dance class. We've had lots of his friends over the years. Particularly, he tends to hang out with the guys and we've been fortunate enough to have guys in the class every year. This is the first year, I think, we've just had one young guy, but it previous years, we had two or three of all of his friends and they all danced together. So they has a really great sense of community, but now as they're getting older, they're all going off to different things and they're graduating. So it was nice, I think, for Miller this year that—I'm pretty sure we started the season and he was the only guy in the class. So it was a different relationship

with the ladies, but then we did have...another young gentleman join, and they've really bonded over floorwork.

Further, Jody explained the common bond that Miller developed with this new dancer, named Andrew. When Andrew joined the class, he initiated a 'dance-off' at the end of class, which involves dancers taking turns doing 'free-style' dance moves to music and it has become an enjoyable time for both Miller and Andrew to develop their bond. Jody stated:

So Andrew was new this year, and Miller loved when he came. Because...it was always the girls and Miller [at the beginning of the last season], so not a lot of guys. So when Andrew joined—Andrew's the one who introduced the—and at the end of the dance, let's do this three-minute dance-off. So then you know what? It pulls him into another aspect of dance and encourages more involvement because—and then the two of them—and Andrew's mom just thought it was great too, because now Miller and Andrew have someone to talk to.

Similarly, Kate described this bond over free-styling dance moves at the end of the dance class. She explained:

As a dance teacher, that's what I noticed, that it's like, 'you both want to out-breakdance each other.' So it's like this really interesting, like 'we're buddies, but we're going to try and up the ante.' Like, 'okay, you did that cool move in your freestyle. I'm going to do this cool move in my freestyle.' So they have an interesting relationship.

Kate also described Miller's friendship with Andrew as being both friendly and competitive and that their dynamic encourages everyone to better themselves. Kate also explained the value in having friends who dance at similar levels. She described Andrew as:

Somebody else who's joined the class who has some real good skill as well. So they're on the same level with that. So the competition, it just keeps going. But, I mean, at the end of the day, they both still seem to be good friends.

Jody also explained how this friendship extends beyond the dance classes. Not only does dance provide a context for them to develop a close friendship, but it also allows for them to expand their friend groups at various dance-related events. For instance, both Miller and Andrew attend community social dances for an organization supporting individuals with disabilities and their families a few times a year. Jody explained:

So now Andrew's at those when we go too, so they have that. The two of them will go do dance-offs. And they'll encourage other people to come out. He has a few friends who are not big dancers, but he'll get them out there anyway because they all want to be with their peers...So someone who may not dance will want to out there with Miller, so they'll go. Or they want to be out there with Andrew because it's Andrew's friends from another school. And it just encourages them all to be more social.

With Miller's outgoing and charismatic nature, he is often a natural born leader among his friends and peers. Dance activities provide Miller with the opportunities to exercise this social role and thus better his sense of self and quality of life. In the interview with Jody, she described her son's leadership role:

Because he's so social, and Miller likes to do what Miller likes to do. And if you're not a dancer and you're his friend, he's going to dance anyway and he'll just, like I said, try and get you out there...And I think his friends appreciate that about him. I know the parents do. Because the parents all make comments about how big Miller is.

Moreover, Jody also explained that the organization who supports individuals with disabilities and their families asked Jody and two other parents who also have children who are leaders among their peers to help organize the dance events for their organization. She explained:

And that's why the [organization] contacted myself and two other parents, because Miller and his two other friends are kind of like, I don't want to say the ring leaders, but they're the personalities that will get the others out there.

In a similar light, Jody also explained how dance allows Miller to encourage others to participate in settings that are unrelated to dance. For example, she described how Miller motivates those around him at sports games. She stated:

So we put you out in big social surroundings. Yeah, you just bring other people into Blue Jays games, when they do their stand up and dance. And you know, you get a lot of people around him who high five, and they come and dance with him.

In addition to forming friendships with his peers, being involved with dance has also fostered a friendship between Miller and his dance instructor Kate. This friendship is mutually beneficial for both Kate and Miller and has provided Miller with someone from whom he can learn and trust with his dance practice. When asked what he liked about dance class, Miller responded, "I like Kate…because she [teaches] me all the moves." In the interview Kate, she described the nature of her positive working relationship with Miller:

Quite often, he'll come to me and he'll be like, 'What about this song?' Or, 'I want to do this or try this.' So I try and incorporate some of the music he likes...over the years, I've tried to be like, 'All right, you like Michael Jackson? Here's a Michael Jackson song, Miller. This one's for you, Buddy.' And he likes to show me his moves as well. So as much as I'm teaching him some moves, that if we have a water break or something, he'll

be like, 'Well, come on, look at my cool move like this'...And he makes me laugh [laughter]. So it's a good back and forth.

Kate also mentioned that she aims to create class environments where she can collaborate with Miller and her other students and maintain a safe space where dancers can work together and share openly with one another. She continued:

And I think making time for your students in class like that for them to have those moments where they can share something with you, so it's not always you dumping stuff on them, is key to a good back and forth relationship because then I think he feels he can trust me with showing me his moves. And dancing, you can be very vulnerable because you're opening yourself up to criticism. So I think he feels it's a safe place, which is great.

From her interview, it was clear that Kate is dedicated to ensuring Miller develops and enjoys his dance practice, which creates a trusting relationship between the pair. When explaining one of her approaches to supporting Miller, Kate explained the value she places in meeting her dance student at his level.

Another way that Kate helps Miller's dance practice, is by taking control of the class and ensuring that she is providing guidance to each individual dancer. For instance, when Miller was getting frustrated by receiving corrections from people other than his instructor, Kate acknowledged the issue and asserted the value of her role in the dancers' development.

Sexuality – "[I] like beautiful ladies and they like me too". Along with friendships, recreational dance pursuits allow Miller to meet women as sexual partners or potential romantic interests. Like many other young men, Miller is eager to find someone with whom he can build a

sexual and romantic bond. Miller stated, "[I] like beautiful ladies and they like me too." Miller regularly expresses his desire to have a girlfriend or wife. Jody stated:

Because he wants a girlfriend, so we have to go to where the girls are. And there [are] a few there at the dances that are...his age and [with a bit of a] strong personality, more than him. Because he's more the laid-back [one].

Dance-based activities provide Miller the opportunity to meet and form connections with potential romantic partners. For example, when one of Miller's female friends sees him at dance class, he said she is "real happy and excited" to see him, often running to him and giving him hugs and saying his name in an excited manner. In this way, dance provides Miller with the opportunity to form close and positive relationships with women. In addition, at a dance social for individuals with Down syndrome and their friends, he met a young woman with whom he danced and shared a connection. He stated happily, "I went to the Down syndrome dance, too. And the lady kissed me." Jody told Miller in an interview, "You were dancing with a girl, and at the end of the night she came and kissed you on the cheek." She went on to explain, "He thought it was the best thing ever. He was like, 'I like that!' It was really funny." In this situation, the dance social allowed Miller and this individual to meet and create a romantic connection. Similarly, Miller was also able to connect with another female at his high school prom, which involved social dancing as well. In the interview with Miller, he stated that he brought a date to his high school prom and danced with her and her friends and slow danced with his date, all of which he really enjoyed. Jody further explained:

So he wanted to go to prom, I said that's fine. He wanted to find a date, and I was going to work on finding somebody that I knew. And there was this girl who worked at Boston Pizza at the time. She was the hostess. And she was in grade 11...and he saw her at

school and asked her...Oh yeah, they had a great time. She went out with us, she came early, we went and had pictures done, and so it was great...[I was] impressed with her for saying 'Yeah, I'll go' it's like—but you know, it's kind of a bonus too. If you're in grade 11 and you really want to go to the prom because you have grade 12 friends, it's kind of a door in. So I'm sure it worked out for her that way too...But she wasn't embarrassed. She wasn't embarrassed to be his date. I mean, she sat with him and ate, she rode on the bus with him, they had pictures taken with her group and her peers and friends. So it was great.

Role models – "I help them all the time [at dance]". Along with friendships and romantic interests, recreational dance has also provided Miller with role models as well as allowed him to be a role model for others.

Role models in others. Through his experiences with dance, Miller has gained male role models, which has been very valuable to him and his development. In Miller's dance classes, there are volunteers who participate in the dance class, supporting the dancers either individually or as a group. Most of these volunteers are female, however this past year a male volunteer, Dale, supported the dancers in Miller's class. Miller and other dance students looked up to Dale and his charismatic and easy-going personality and he became a role model for Miller and other dancers. In the interview with Miller, when asked why dance makes him happy, Miller responded, "Because I like to see Dale." Kate described Dale and the sadness expressed by the dance students towards him moving on from the dance program. She stated:

He loves that guy...Devastated that he is moving...That was a huge blow, that I think it was so wonderful—even though, Dale's the first to say that dance is something foreign, I

think, to him, but he gives everything he's got...He was game for like, 'All right. You guys want me to freestyle? I will try and freestyle.'

Kate went on to explain the value that Dale especially provided the male dancers:

It was nice for the guys in the class to suddenly have that male role model come in. And I guess having that male role model or male mentor is different for a male. And you know what? That's across the board for all of our classes, that the more older guys we can get involved—even older, even 16 or 15, the younger kids just respond to them so well. Guys and girls, but particularly, the young guys. So it's really good for Miller to have that.

Role model to others. Dance also allows him to become a role model to others. For instance, many of the dance students in Miller's tap class are younger than he is and look up to Miller and his charismatic and kind-hearted personality. Miller particularly developed a strong bond with Shawn, a young dancer in the class. Miller explained that when Shawn was new to the dance class, Miller would "help them all [the] time" by greeting him and other dancers outside of the studio, holding their hands, and bringing them to the dance studio. Jody further described the close bond that her son and this young dancer formed. She expressed:

When Shawn was new, he was really shy. And so Miller would like, 'No, come on buddy. It's okay buddy. Come with me.' He'd meet him right outside in the lobby-way. He would meet them, and then he would take them in so the parents wouldn't have to worry about—sometimes it's that separation from the parents. But then he would step in and he would take them and they wanted to be with Miller, so they would go. So I mean, and that was the same with [another dancer] too. [She] would always hold his hand in dance. So I mean, it's easier for the other parents to do those transitions.

Kate also talked about Miller's mentor-like relationship with Shawn in tap class. She explains:

He's particularly helpful with the one little boy in tap class. He's always partnering up with Shawn, and always like, 'Okay, buddy. Come on, let's do this.' Like, 'Come on across the floor.' And like, 'Come on toes on the—getting him over there and whatnot and just trying to be silly with him.

When asked how this relationship began, Kate stated:

I think he started partnering up with Shawn because—there was one day a long while back that we didn't quite have enough dance buddies for everybody, and it was like, 'Oh, okay. Well, can you go with him?' 'Yeah, I'll go with Shawn.' And then it's just turned into this weekly thing; they are partners. They don't need a dance buddy, they're actually matched skill-wise very well, which is perfect because they both have, I guess, that sense for—tap is hard for some people to understand the front of their foot and the back, separating, but both of them seem to have that good knowledge and ability, a combination of it. So they're a really good partnership, coming across. So he's just a good—I don't know, he's like Shawn's dance buddy sometimes. He takes on that role that we normally have the volunteers for, which is really cool.

Furthermore, Kate said that Shawn looks up to Miller who serves as a role model to Shawn. She continued:

Yeah, almost big brother sort of thing because if Miller does something silly, then

Shawn automatically just wants to copy it and do the same thing over again. And I'll be
like, 'All right, focus boys. We got to get across the floor.' Yeah, just two friends
hanging out, one looking up—yeah, I'd definitely say sibling, older brother thing.

In addition to Miller being a role model in his tap class, he also acts as a role model in his volunteer position at the community youth dances. During the dances, the children attending

the socials look up to him as they are impressed with his dance skills. In the interview with Gail, the community member who organizes the volunteer chaperones for these days, described how the children attending the dances feel towards Miller. In her response, she stated, "For the children, they show respect, because he is very talented." She also explained that many children want Miller to teach them how to replicate his dance moves, saying things like, "Show me.

Yeah. Come show me how to do that." Gail described Miller as being happy to take on a role-model position by stating, "I think because he wants to show the children how to do his—because he's got some nice moves."

# Belonging – "We're always being introduced to other people [through dance]"

Recreational dance involvement has also provided Miller with a sense of belonging.

More specifically, several people who are involved with his dance activities are people he sometimes sees in the community, which contributes to his sense of belonging and involvement with a community. For example, Miller knows several people who are involved in the monthly youth dances. Gail explained, "The DJ knows him...Then he's got [his worker] there. [His worker's] daughter often runs our snack bar, so he knows her...And then the scout leaders this time, they were there. He knew them." In addition, Jody explained how his son knew some of the dancers from his dance classes and the monthly youth dances in the community. She said:

And he sees the—he sees a lot of the individuals outside. So the younger kids—he volunteers at [a local high school], so he sees them...some of the younger kids from his age group are there...So he'll go into their classes and that to them. And so that brings him more into that school aspect...He does see the community kids too, out in the community. We run into them everywhere. Like, we were garage sale-ing on the weekend, and [another parent] was like 'Oh, hi!' And it's like, 'My son tells me about

your son. He volunteers at the dances he goes to'...So we're always being introduced to other people.

Similarly, recreational dance has also given Miller a sense of belonging through his peers and fellow dancers. As a result, his confidence and strong sense of self lead him to use his dance pursuits to create more inclusion of people with ID. When asked how Kate thought Miller felt when he is dancing, she replied:

I think he generally feels happy, and just one of the group, just included. When you were describing the question, the thought that came to mind was our [local community parade] last year. It's open to anybody and you come, you learn the routine, everybody gets a free t-shirt and then we dance a really long way [laughter]— a really long way down through [the town]...he just was happy to be a part of something.

Kate continued to describe the sense of pride and identity that Miller expresses towards being part of his dance studio. She said:

And I think he likes being recognized as a dancer from our studio, and I find that with a lot of our dancers [in the integrated dance classes]. Our other dancers are happy as well, but our core [integrated dance] group is just so proud to be one of our dancers ....Sometimes I bump into dancers at the grocery store and whatnot. I haven't bumped into Miller lately, but our core [integrated dance] group is the one that I would randomly bump into and they'd be wearing our shirt or they'd be wearing our jacket, and they'd be like, 'Look what I'm wearing, Miss Kate!' Miller is always representing because he's a dancer...Every year, I have to tell him, 'Don't wear your costume before recital,' because he's usually so happy that this is his costume. He wants to show it to everybody that 'This is my show coming up. This is the thing that I'm a part of.' It's like, 'No, don't wear it.

You're going to get it dirty [laughter]!' And his mom will come in and be like, 'See, Miller, I told you Miss Kate said, 'Don't wear that shirt'...He's just so proud and happy to be a part of it, that he wants everybody to know, which is awesome and I think that in the classroom when he's focused and whatnot, he's engaged and learning, but then when I see him at the parade and in the way that we're even talking about things like that, like he wants his friends to come to recital and this and that. And it's like, Okay, you're happy. You really feel like you're a part of something.

Kate also highlighted the sense of pride that particularly the dancers with disabilities who attended the integrated dances express, as opposed to the dancers without disabilities who participated in the non-integrated dance classes. She explained:

I think with our [integrated dancers], there's a really strong sense of pride. Whereas other dancers, they come, they take their class, and it's a class—they're happy to be a part of it, but there's not that gusto behind it, unless they're one of our dancers who's danced with us for years and takes 10 classes a week, but you don't get that kind of enthusiasm for somebody who's here an hour-and-a-half unless it's that group.

Kate continued by describing the sense of identity as a dancer that many of the dancers who attend the integrated dance classes express. She stated:

It's like you would never know that you're only in studio 45 minutes because those 45 minutes are everything, which is awesome, that real appreciation for, 'I am a dancer.' And it's awesome to see that it's not, 'I'm a dancer [in the integrated class].'...or, 'I have a dance buddy.' It's like, 'No, I'm a dancer.' It's like, 'Oh, yes, that's amazing [laughter]." When they say that, like, "All right, wrap it up. We're good [laughter]. I can go home now."

Lastly, Kate mentioned the sense of belonging that both Miller and his friend Andrew express when talking about the free-style dance-offs the pair initiate after dance class and at various dance socials. This is indicated by the dancers referring to their "crew" or their "b-boy crew."

Inclusion – "No. I'm going to be in the front". Miller also experiences inclusion due to his involvement with recreational dance. In other words, Miller's dance experiences allow him to more fully participate in his community and as a result, create more awareness, tolerance, and inclusion among society.

Overall, when Miller is interested in engaging in a leisure pursuit, with the help of his family, he is met with support from others, namely the employees at various leisure-related venues, such as go-karting or outdoor ropes courses. However, like many individuals with ID, Miller also experiences social exclusion from others. Jody briefly described the social exclusion that Miller experiences. She mentioned the physical distance that others take towards Miller in busy public spaces and the judgments from other parents towards her supporting her son in participating in life as fully as possible. Most of this criticism come from other parents of children with ID who tend to have their children spend a lot of time at home and less engaged in daily mainstream society. Jody stated:

There's so many of his friends—and it's like, they'll sit at home on the computers. They won't go out. 'You guys want to go to the beach? You guys want to go to Wonderland?' Any they're like, 'No, no, no. That wouldn't be a good place for them.' Well, why not? Why is the world not a good place for them? I take him wherever.

Although Miller and others with ID continue to experience social exclusion, Miller's experiences with dance seem to provide him with social inclusion and community integration.

When describing her son's volunteer participation in the monthly youth dances, Jody discussed

the social benefits of Miller's involvement, not only for himself, but moreover for the youth who attend the dances. Jody said:

And I love for him to be a part of the mainstream. Because I think it makes other people more comfortable with him, and more comfortable with others with special needs...They don't have a stereotype, because they meet Miller and they're like, 'Well, yeah, so what?' You know? And there's so many kids at those dances, they're huge. Yeah. So I don't keep him hidden. I like to push him out, [crosstalk], push him out there—and make society deal with him. Not hide him so that it's, 'Oh, oh, oh,' or, 'Poor him,' or whatever. It's like, 'No, here he is, deal with him.'

Similarly, Gail also mentioned the value in having the children at the youth dances interact with Miller. She explained, "We want him to come. Number one, he deserves to come out and volunteer. But the children [also] need to see that they all have a gift."

Not only does Miller's involvement in dance create more community inclusion, but Miller's confidence and ambition has disrupted typical social and community norms and thus, in a sense, has helped Miller develop a sense of belonging from himself. For instance, when Miller's dance studio performed in the locale parade, not only did Miller perform with the dancers from the non-integrated classes, but he also insisted that he dance in the front of the group, instead of the back of the group where he was originally told to dance. His mother proudly stated:

The guy, one of the other lead dancers, one of the really good dancers, kept saying, 'No, you go back here,' and he's like, 'No. I'm going to be in the front. I'm going to be a leader.' It was pretty funny. But no, he has no issue with doing that. And I was very

impressed. Because I wasn't sure how it would go. Because we hadn't done that, and like I said, the dance was for everyone [who belonged to the studio]...Oh, yeah. He loved it.

### Strengths

In addition to connection, another major aspect of Miller's experiences with recreational dance is related to his character strengths. Miller's dance engagements allow him to develop and express different strengths and facets of his personality. The five main strengths that dance helps Miller cultivate are his zest for life, kind-heartedness, sense of humour, independence, and ambition.

## Zest for Life - "Just out There Giving 'er"

Dance participation allows Miller to develop and express his love of life. Miller's mother said that her son often dances outside on the front lawn of their house. She stated:

He dances in the driveway all the time. So my neighbors around here, the new ones, are kind of like [staring] when they drive by the first couple of times. But people will stop at the four-way stop, and they look because they can see him dancing. And I get comments from people all the time, it's like, 'I love driving by your house because he's out dancing.' Because he makes other people feel good. Because he's out there and he has no care in the world, and just dances. Just out there giving 'er.

The rest of the data on this theme can be divided into three sub-themes: charisma, life of the party, and natural performer.

Charisma – "[I like] making people happy". One of Miller's prominent strengths is his charisma. When asked why he liked dancing for others, Miller responded saying that it makes people feel happy and "Because [I like] making people happy." Furthermore, his dance instructor

described Miller as "very outgoing, personable guy". Kate also described Miller's positive and charismatic nature in the following way:

You can't be cranky. It doesn't matter what happens before class, he's going to come in smiling and it's going to be like, 'All right. What are we going to—' it changes the tone very quickly. I don't think I've ever really—only a handful of times seen him come in and it's like, 'Okay, you're not your happy self. You've had a rough day. Okay, so what can we do now to make you laugh because you always make the rest of us laugh?'

Life of the party – "Once he starts dancing then they come over". Miller's zest for life and charismatic personality often attracts people to him, including in his experiences with dance. For example, Jody mentioned that her son would always be "life of the party" at dance socials or events that involve social dancing, such as sports banquets. Similarly, Gail said that many of the children in the youth dances would watch Miller dance on stage or watch him dance in a crowd around him on the dance floor. When Miller volunteered accompanied by his worker, Gail explained, "He was up on the stage, getting the kids going. They were all watching him…There's 200 of them running around, and once he starts dancing then they come over."

Natural performer – "[I'm] a star". A final aspect related to Miller's zest for life that was prevalent in the data was his characteristic of being a natural performer. In the interview with Miller, he identified himself as "a star" and admitted that he sometimes likes to 'show-off' for others. Furthermore, Gail explained how the children at the youth dances are drawn to watching Miller dance saying:

They enjoy watching Miller dance. We all do. We all do. He's very talented...I think people seeing how talented he is, they all want to see what he's doing. 'How do we do that?'...I think he enjoys being, I'm going to say, the centre of attention. But not in a

negative way. They children are all seeing how great he is, and [saying things like] 'Oh, show me that' And, 'was that ever cool? Look at him. Is he ever good?'

### Kind-heartedness – "[I'm] really helpful"

Along with having a zest for life, Miller is also kind-hearted. For instance, Gail explained one of the strengths she sees in Miller. She stated:

I've seen a lot of compassion. And I remember, it was at baseball, not at the dance, I twisted my—my bones are well over 50. I hurt my knee and I went down. And he got out of his car and he flew. 'Miss Muller, Miss Muller!...Are you okay, are you okay?' So he's got a good heart. He wants people to be happy. He wants to help.

Among other characteristics, Miller described himself as "really helpful." When asked about the ways in which he was helpful, Miller replied, "I like carrying bags" and explained how he sometimes pushes the shopping cart for his mother. The data shows that Miller is also helpful to others through his dance involvements. For example, when asked how he is helpful in dance class, he mentioned he helps move the ballet barres for the class for the warm-up in tap class. Moreover, in the monthly youth dances, he is very compassionate and helpful towards the dance attendees. Gail explained that he is there for the children when they get hurt and also stated, "And [he's] like running around helping people, like clean up time. And 'What can I do?' He's just sweet. I wish we had a world full of them."

# Sense of Humour – "[I'm] Funny"

One of Miller's strengths is his strong sense of humour. Not only did Miller describe himself as "funny", but even in the short time that I spent with Miller, it was clear that he had a strong sense of humour and enjoyed making others laugh. For example, when I asked Miller why two of his female friends like him so much, he answered, "Because I'm a heartthrob." In

addition, when I was taking photographs of him in one of his dance classes, he would occasionally turn to the camera to make balletic poses. Gail also mentioned Miller's great sense of humour. One of Miller's responsibilities in his cleaning job is taking out the recycling. Referring to a time when Gail was supervising him at the centre, she said, "The thing with the recycling, like, 'aren't you going to help me?' Right? Just the way he interacts with you. He has you in tears. He's just hilarious." Gail continued to talk about Miller's sense of humour when she stated, "Different things that I have noticed. He is funny. He's absolutely hilarious. Setting his mom up with strange men [laugher]...she's happily married now, but she couldn't go anywhere without him trying to set her up with somebody [laughter]."

The data reveals that Miller's dance experiences offer him a platform to express sense of humour and make others laugh. For example, Kate described her dance student's sense of humour in the dance classes. She said:

With Miller, I used to say 'combo' a lot [short for combination], but then he jumps at me and says, 'McDonalds! Where's my French fries and burger [laughter]?' And every time I go to say it, he's like, 'Don't say combo.' I'm like, 'Okay, not a combo, it's a sequence' or something like that, which is hilarious, that's just how he connects it.

Miller is often seen as a 'jokester' in dance class. Kate explained, "In tap class, I'd say he's a little bit more of the jokester because I think he's with some younger dancers and he likes to make them laugh." Kate also described Miller's sense of humour and 'jokester' persona with the other dancers in the class. For instance, in tap class, Miller often tries to make his young friend, Shawn, laugh. Kate stated:

Sometimes it's [for] an audience because he'll crack jokes about me or something like that to the little guy [laughter] and I'm like, 'Just make sure they're kid-friendly jokes there,

Miller [laughter].' But he always has the best of intentions...If Miller does something silly, then Shawn automatically just wants to copy it and do the same thing over again.

And I'll be like, 'All right, focus boys. We got to get across the floor'.

### Independence – "He doesn't see the barriers at all"

Another strength that the data revealed is Miller's independence. When describing her son, Jody talked about Miller's independence. She stated in a heartfelt manner:

He speaks for himself, which is good. He's very independent that way, where he has his own bank card. He can use all of those things. So I don't hold him back from learning or doing anything, because I want—and my question that I ask myself all the time is, 'Is he going to be okay when I'm gone?' And I know that because of everything he can do, he's going to be okay. Because he can do all of those things on his own without having to be told by me. And he's comfortable with doing it.

Jody also talked about her son's desire to gain more freedom and independence that he already has in the following way:

He wants to live on his own...And he's interested in driving as well...Yeah. He doesn't see the barriers at all. So yeah, he's determined he's buying a house and getting married. And those kinds of things are great, but at the same time, you know what? We have our obstacles. Like paying the bills and stuff like that. So we've told him that the basement, when we just get rid of the other ones, will become his place. So we'll turn that into an apartment, because we have two bedrooms down there and a living room area. So that's our plan so he has that independence. Because he'd really like to...he wants to leave home.

Dance provides Miller with a context through which to gain more independence in life. For instance, Gail described the sense of independence that Miller might have experienced by volunteering at the monthly youth dance without being accompanied by his worker, which is something he has recently started to do. She stated:

He looks, and I noticed it more so because [his worker] wasn't there, and that's fine. We don't need [his worker]. We love [his worker]. But he was very laid back for a good hour, and then he started to [get more into it]. But I think, you know you had said it's new. Right? He's there on his own. 'Am I doing okay?' And yeah, he did great. He does wonderful, and it's nice.

Along with gaining independence from volunteering in the youth dances, Miller also aserts his independence in his dance classes. For instance, Kate said:

I think sometimes the dancer's behavior changes based on if they can see their parent there or whatnot. Because I know a few times—I mean, I know Miller—he loves his mom, but he'll be like, 'Mom, go away.'... [Or] she'll be like, 'Miller, you're on the wrong foot' And he'll be like, "Don't tell me that!'...When he's with that older group in the different space, he's like, 'No, no, no, no. Don't be watching me. I'm going to be in here dancing.'

Overall, dance as a leisure pursuit seems to offer Miller a sense of independence and solace. For example, when asked how she think Miller feels when he is dancing, his mother responded in the following way:

Oh, he's definitely happy. That's his space that I'm not welcome into. Unless Kate invites parents in, he will tell me to go, and leave. So it's independence. So you know, that dance is his independence, his zone, not mine.

# Ambition - "He was going to [dance] at the front of the group with the other boys"

A final strength of Miller is his ambitious nature. The data consistently shows that Miller likes to challenge himself and has a lot of determination. His mother described Miller:

He always challenges himself. Like he comes up with a lot of things on his own. His 19th birthday? He hates heights. He wanted to go tree-top trekking...So I had a friend at the front, a friend and myself at the back, and we got him through all the courses. Because he's always challenging himself.

Similarly, Gail also described Miller's ambitious nature. When asked how she perceived Miller thought of himself, she replied:

I've seen him frustrated and angry because of his lack of ability to do something... I know he knows he has challenges, but how he overcomes those challenges with his willingness to please and participate and do whatever makes him happy.

Recreational dance involvement encourages Miller to challenge himself and use his ambitious nature to overcome those challenges. For instance, Kate expressed Miller's attitude towards being motivated to work hard. She explained:

He doesn't run away from hard work. He might grab his drink of water from the fridge, but he's definitely not one [to sit on the chairs]...He's always like, 'Okay, what's next? It's hot in here, but what's next?' So he's good that he keeps going.

Furthermore, Kate described her dance student's determination not only to perform in the local parade, but also lead the group of dancers through the parade. She explained:

It was a very jazzy type dance. So it was moves that he wasn't necessarily familiar with, but man, was he determined to do every move and he was going to be at the front of the group with the other boys.

Along with dance class, his volunteer position at the monthly youth dances was another dance-related pursuit that developed Miller's ambition and motivation. Gail said, "He's very mature. I thought he'd be immature, but no. he's very mature and takes his job—he takes his responsibilities seriously."

#### **Personal Growth**

The third major category of themes that is demonstrated by the data is personal growth. Much of the data explores themes related to Miller's personal growth, which can be further categorized into sense of self and proficiency. This section will focus on answering the secondary research question of this case study: *In what ways, if any, does recreational dance impact an individual with an intellectual disability as it relates to his sense of self?* 

## Sense of Self – "I am nice and sweet and I [am] good with the ladies"

This section will present the many ways that recreational dance impacts Miller's sense of self. More specifically, I will outline Miller's sense of self and describe various related aspects of his sense of self, and how his dance experiences impact each of these elements. First, I will describe Miller's sense of self. Then, I will present two related aspects to his sense of self: confidence and social feedback. Lastly, I will outline Miller's experiences with barriers, and explain how his involvement with recreational dance helps him overcome these barriers.

Miller has a positive sense of self and described his sense of self with simple descriptors. When asked how he thought of himself, Miller answered, "I am [a] nice guy...I am nice and sweet and I [am] good with the ladies." Also, through his interview, he described himself as "a star", "a hot guy", "really helpful", and said that other people like to be around him. Miller seemed to think of himself in a positive light, however her also expressed a couple of aspects related to his experiences that he would change. For instance, Miller said, "I [would] like to get a

job." In addition, Miller would like to be able to drive a car, which he cannot do because of his ID and acquired brain injury. Miller stated, "I can't drive...because Mom said I can't read about driver safety. I don't remember how to [read] because of the accident."

From Miller's sense of self, it is clear that he views himself as kind, attractive, helpful, charismatic, and a performer. In addition, he values employment, independence, and freedom, which are difficult for him to attain due to stigmatization and disability-related barriers.

The other informants described the ways they believe Miller sees himself. In an interview with Jody, when asked how she thought Miller viewed himself, directing her response to Miller who was present for the interview, she responded, "You're very confident with who you are...I think he knows who he is. Pretty comfortable with who he says he is." and said that he thinks of himself in a very positive way. In addition, Gail described Miller as having a good sense of self and positive self-esteem and also stated that "he's fully aware of his abilities and disabilities." Similarly, when asked how she thought Miller sees himself, Kate responded, "I'd like to think he's got a really positive sense of self because he gives the perceptions that he's always happy and ready to go and whatnot. So I hope he feels that way." When I told Kate that Miller expressed a positive sense of self in the interview with him, she responded, "That's wonderful because that's the kind of persona he gives off and if you can internalize that's a great bout of confidence to have."

Jody discussed her perception of Miller's sense of self as someone with an ID. She explained that her son is not only comfortable with himself in general, but he also is comfortable with his ID. She stated:

He has no issue with who he is. And you know what? And who he is as a person with Down syndrome as well. Because if we go to—so we were at Disney. There was a lot of

people there with special needs. And there was a girl they were swimming with, and he goes, 'Oh, hi! I'm Miller. I have Down syndrome too.' And then the two of them hit it off really great. It was a really good dynamic. But anywhere we go—if we go to the hockey tournaments when we're away and he meets people, and he can recognize others with Down syndrome, and he'll introduce himself, 'I have Down syndrome too.' And talk about that, whereas— and not a lot of people can do that or do do that—because not everybody's comfortable with that...He just sees himself as Miller, and he has Down syndrome, and he owns it. So I think whether he's at dance or anywhere else, he just kind of own who he is.

Gail addressed the impact that dance has on Miller in terms of one of the ways he identifies himself. She mentioned that Miller has adopted the self-identity of a dancer, which his involvement in the monthly youth dances has helped to form. She stated, "[Dancing] gives him that recognition. Oh yeah, there's that kid who dances."

Confidence – "[I'm a] hot guy [and I] got [the] best moves". Not only is Miller confident with who he is, but he is also confident in his character and abilities. For example, when asked about his favourite things in his dance classes, he said, "I like hip hop because I got [the] best moves." He also expressed great confidence with romantic interests, saying that he's a "hot guy" and that women like him. Miller's mother elaborated this theme. When asked how she thought Miller thought of himself, Jody responded, "Well, his self-esteem is huge...He doesn't lack confidence in any way whatsoever."

Miller's dance experiences impact his self-esteem in a positive way. Not only does dance allow him to express his confidence to others, but it also further develops his self-esteem. Jody

explained how dance increases his self-esteem by using the parade in which Miller danced as an example. She said:

I think it brings up the self-esteem, because last year was the first time he danced in the parade. And I wasn't sure how that was going to go because that's not part of the [integrated dance] group. That is she's formed a routine. The routine is being danced by all dancers, from whether it be the little kids, to our really, really, really great, amazing, older-kid dancers. And you know what? He did it. He kept up with it.

Miller's experience taking recreational dance lessons has also allowed him to express and foster his confidence. Kate explained:

In the classroom, he's definitely very confident. When you're doing moves and whatnot, I'll be like, 'Well, okay, we got it, but let's try to fix this.' 'No, I got it. I totally got this.' And I'm like, 'So close. Can we change this little thing?' 'Nope, I got it.' 'Okay [laughter], you know what? That's all right.'

In addition, Kate addressed the confidence that Miller shows with his excitement to show his free-style dance moves at the end of the hip hop class. Kate described Miller and his friend, Andrew, saying, "I think it's that whole—dancing, you're exposing yourself, and if it's not a set move, they're nervous. Whereas the two of them are like, 'The heck with it, we're doing anything we want'."

Along with the dance classes, Miller's volunteer position at the monthly youth dances also seems to contribute to building his self-esteem. Gail said, "I think at the youth dance setting he's assuming some responsibility which is good for his self-esteem...It gives him confidence." Furthermore, Gail commented on the confidence that participating in adult socials seem to

provide Miller. Describing what Miller might be thinking at these dances, Gail explained, "I'm great. I'm good. I'm the best.' It gives him the confidence to go talk to pretty girls at the dance."

Social feedback – "A well-loved happy young man". One of the predominant aspects that informs one's sense of self is the way that others view that individual. The data demonstrates that Miller is well-loved by many people, including both his family and friends as well as his larger community. For example, Miller explained that his friends and peers are always really happy and excited to see him. Furthermore, when asked how she thought his fellow dancers would describe him, Kate responded, "They would say he's a funny guy, a bit of a goofball sometimes. Yeah, that he likes the ladies in the class...But yeah, he likes to crack jokes and whatnot, but then he can jump in and be focused for the class. So I think they just see him as a very outgoing friendly member of the class." Similarly, Gail described Miller as "an amazing, well-loved, happy young man" and said that he is greatly admired by many of the people at the dances. Gail continued to address the acceptance of Miller from others, saying:

He wants to be accepted. And I really think he is. I firmly believe he is a well adjusted, happy [individual]...We all love Miller. I'd go get him myself if Jody couldn't bring him. We all want him to get out and interact.

Barriers – "We need to find someone more like you". As previously outlined in chapter two, many people with ID experience barriers to fully participating in life. These barriers, both disability-related and socially constructed, can often negatively impact one's sense of self. Therefore, when exploring Miller's sense of self, it is important to consider the barriers that he faces. Almost all of the barriers that Miller experiences are socially constructed and due to stigmatization towards people with ID. The only disability-related barrier that was discussed in the data was his lack of ability to drive a car.

One of the major challenges that Miller faces is his desire for a girlfriend or wife. This desire is felt by others. For instance, Gail said, "I know he gets frustrated when he sees his little brother get a car and get a girlfriend...You know what I mean? He wants that." Miller's mother is very supportive of her son finding a partner and having them eventually live in her basement; however, finding a suitable match has been a barrier for Miller. Jody explained:

We have a few friends from hockey that we've met who are married and they live in their parents' basement, And I have no issue with Miller getting married, or no issue with any of that, you know? And having an apartment in the basement. But it has to be someone that I can be up here, and know that they are okay. Because his idea of marriage and a relationship is, you know what—because we have two rooms, and like, 'Well, she'll have a room, Mom, and I'll have a room, right?' It's different, so. And I want to know that that environment is always going to be okay...And we talk about that, right? That's probably one of our most difficult conversations.

With Miller present in the room, Jody explained the barriers Miller faces with finding suitable people to date. She said:

That's one of the things we have to talk about, though. And that's a difficult conversation to have, is because he wants to date girls who, I don't want to say are out of his league, but we need to find someone, and I tell him, we need to find someone more like you. Someone who has the same interests as you, or maybe somebody with Down syndrome like you, so they understand. I mean, you don't want to set that barrier, but reality is what it is, right? And I don't want him to get hurt. So we do have to have those conversations because sometimes when you're—like when we're at my ball banquet and there's cute blondes and you know, I need to remind him that, 'You know what? You're being too

creepy,' or yeah, or, [he's like] 'I want to date her,' and he'll keep going up, [he's] like, 'You're cute,' and he'll maybe be too much in their space. I'm like, 'Okay, so that's inappropriate,' because in his world, and in his eyes, he does not see—'Well, why wouldn't she want to date me?' Like, 'I'm a great guy.' That's probably a barrier that I think we have, so that's why I try to go to more socials with peers. So that we can kind of make those connections, rather than him hitting on the poor older girls and me having to say, 'Oh, Miller [laughter].'

Jody also explained the importance of keeping her son protected as he enters the dating world. She stated, "And then there you have that other side, though, because you have so many creepers, because these guys are vulnerable, right?" Similarly, Gail mentioned the risk regarding Miller's vulnerability when she said, "Miller would be easily—not abused, [but] taken advantage of...because he's so kind hearted."

Even though Miller experiences barriers with dating, he is very confident and ambitious to find a partner. As indicated by his involvement with dance, recreational dance pursuits have allowed him to meet and develop connections with women.

Stigmatization – "I [would] like to get a job". Like others with ID, Miller experiences stigmatization because of his ID. One of the major areas that Miller faces stigmatization is with employment. When asked if there is anything he would change, Miller replied "I [would] like to get a job." Miller has had several jobs in the past, however in an interview with Miller and his mother, Jody explained, "When the pay increase happened, they got rid of their employees with special needs. Miller then stated, "Yeah. I'm a little upset because of that."

Miller has a weekly job of cleaning the youth centre as well as various volunteer positions in the community, however Miller and other respondents expressed his desire for a full-

time job. Gail explained that she often asks Miller about the success of his search for a job. She stated, "It'd be so nice if he got a job. He wants a job where he gets paid. We do pay him, and in his mind—like 50 dollars a month, he comes in [to clean] every week...[But] I know he wants a real job. They're out there, they just got to give him a chance."

Even though Miller faces stigmatization, the respondents share how Miller resists stigmatization. For instance, when asked for what she is most proud of her son, Jody stated:

How far he's come. Because when he had the accident in 2003 a psychologist said, 'People like him get locked up.' Because his behavior for three years was really bad from a head injury, right? So, I mean, to show them and prove them all so wrong, and like he's held a job. He does time-keeping at baseball, he goes and score-keeps for [a family friend] at his hockey games—and he plays hockey, and dance. He doesn't let any of that stop him. Even though society and professionals were saying, 'This is the way it was going to be,' He's nowhere near the way they said it would be. He pushes himself. And we push him too, to do better than that. So I'm most proud of the fact that he's willing to push himself, and willing to step out, and that he's so accepting.

Jody continued to say, "People love when they meet him because they're like—'Wow', because he doesn't let the world stop him and he shuts down all the stereotypes of Down syndrome."

Jody provided an example of a time when Miller changed the views of others towards people with Down syndrome. She shared:

We belong to a group that goes to Canada's Wonderland. And so we get together with a lot of other groups. And there was a family we met probably four years ago now, because their daughter's just four, and when they had her-- and you know, it's such a shock when you're first put into that. I knew in advance that Miller had Down syndrome. So before I

even had him I knew, so it was no issue for me, but they had the whole shock of it. And then they came to Great Wolf Lodge and they met Miller. And he said meeting Miller was probably one of the best things that could've happened for him and his family.

Because the doctors tell you, 'They may not talk. They may not walk.' I mean, and I got the same story as well, 'They may not do this.' And then they meet Miller. This guy played hockey, so he played hockey right up at almost professional. And Miller's like, 'Yeah, I play hockey! And I do this.' And that made him—they left that weekend feeling so great, and we've actually become quite close with them.

Jody also addressed the stereotypes of people with Down syndrome and how she supports Miller being fully included in age-appropriate activities, even though many other parents of people with ID place more limits on the nature of their children's social activities. She exemplified this when she stated, "Let them be an adult...I play baseball, we go and we have a beer with the team. And [Miller] comes with me and has a beer, but a lot of his friends' parents are completely appalled at the fact."

Miller's involvement with recreational dance has also given him a platform to resist stigmatization. For example, Miller's volunteer work at the monthly youth dances has allowed him to show others his strengths, abilities, and personalities as well as demonstrate that his wants and needs are no different than others. Gail explained, "We were really kind of worried that, I think maybe Jody was, on how children would treat him, being different. They were wonderful. They were...They're polite. I think they realize he's different, but they don't judge." Furthermore, Gail stated that dance is important for Miller's sense of self as it maintains his high level of self-esteem when asked and allows him to show others his abilities and strengths. She explained:

Because it's getting him recognized in our community, it's giving him the awareness that he is good at something. I know he plays hockey on the Special Olympics Team. I know he does dance. I've never seen him play hockey...But I think with the dance it gives him, gives us to see that what he can do, rather than what he can't do.

## Proficiency – "I [got] stage fright. And not anymore...I like [the] stage now."

Along with the construct of sense of self, proficiency was also another theme that was discussed among the respondents. Along with his many positive social skills, Miller is highly skilled at sorting, cleaning, organizing, and doing laundry, which he has used for various work and volunteer positions. Miller's experiences with dance has help contribute to his skill set. Along with dance improving his social connection and character strengths, dance provides Miller with context to develop skills as well. For example, in an interview Miller, he said that his dance instructor teaches him new things and challenges him. Additionally, Miller's mother explained the structure and adherence to rules that her son has gained by participating in tap class. Similarly, Kate addressed the various skills which her dance classes offer Miller. When asked how the dance classes allow Miller to learn new things, Kate replied:

Definitely movement and patterns. We're always—when we're working on choreography, it's all that memorization of everything we've done throughout the year. We've gradually built up, I always call it our catalog of moves...But yeah, I think learning the patterns and the focus, as well, to correct a move. Sometimes, I think for him, the challenge is not maybe in actually doing the move, but understanding that, 'Okay, maybe you're picking up your right foot, but I actually need you to start every move with your left,' or something like that. So I think that's a good challenge for him is applying those corrections in the dance class setting, and there's always a lot of growth from that.

In addition to dance classes, Miller also develops skills from his volunteer chaperone position at the monthly youth dances. Gail discussed the various skills that these experiences teach Miller. When asked what Miller might be learning or gaining from his volunteer position, Gail answered, "I think it's a positive [experience], chaperoning children, helping with clean up...Those are life skills that he's—or work skills that are—and it got him a little job [cleaning a youth centre]."

The benefits of Miller engaging in a leisure activity at the appropriate level of challenge was discussed as well. For example, when asked if she thought Miller might want to have more integrated dance opportunities, she explained that the integrated classes her son attends provide a good balance between challenge and enjoyment. She explained:

Well, because we've looked into other avenues and I have integrated him in other ways. Like, we did integrated soccer. But there comes a point where, you know what? When he's three, and he's playing soccer with the other three and four year olds, it's perfectly great. Because they're all running all over the place. They're all picking dandelions. They're all doing that, but when you get to, okay, now we've been playing soccer, we went up, now we're six and seven. So now is the environment right for Miller? Is he going to have as much fun when he's being left behind? And I don't know that. And I don't want others to, as well, try to feel like they're not accommodating him. Because it gets more challenging for the coaches and stuff. And same with dance. You know what? When we do our dance, it's like, it's their dance. It's everything they can do. And to put him in a group of hip-hoppers, I don't want them to pull back from what their successes can be, and I don't want him to get frustrated with the fact that he can't keep up. Because then he would lose interest in dance. So I mean, for me, this is appropriate, having that.

And then we get included at dance recital. We're a part of the dance recital. We're a part of the parade. So we're a part of all other aspects of the studio. We just have our own class, which I agree with, and I like. I think it gives him more, because it's focusing on his abilities, and not—taking away from what he can do. So it's not like, "Well, this is what the group's doing. You can't do it," so. And this year, Kate was able to, because we had more able bodies this year, she was able to challenge them more than she was the previous year. Because we had lost somebody who had less ability. Because she wants to be all-inclusive, so, I mean, it's kind of a catch-22 sometimes because—this year was great, because she could push them. Last year, it was kind of a—I found it more frustrating because I know he can do more. So it's kind of, where did he fit? When we're in that situation, where does he fit? Because he can do more, but she's got to be fair to the group. Whereas, this year, they were all able bodies. They were all able to be pushed much further than they were the previous years. So it was really great.

Jody elaborated by explaining that if an activity, such as dance, does not have a balance between challenge and skill level, Miller would either lose interest or get frustrated and give up.

Lastly, a couple of the informants addressed the performance skills and skills related to self-assurance that Miller has gained from some of his dance experiences. For instance, Miller explained how he used to be nervous to perform for others, however he has grown to enjoy performing for others. Miller explained, "[I was] a little nervous on that day...I was trying to go on the stage. I [got] stage fright. And not anymore...I like [the] stage now."

Along with gaining more confidence to perform for others, Miller has also developed more confidence in his dance classes. For example, when asked about the progression she saw in Miller over the past few years, Kate said:

He used to stand at the back a lot, but now, he stands over there, which is closer—front, downstage right, instead of being upstage, which is nice because he's putting himself out there more, and he will confidently come to the front all the time...[and with] even that illusion that you're hidden in the bunch, he's kind of broken away from it and been like, 'No, I'm going to stand over there'...there's been a few times, I've said to him, 'Okay,' I want to make sure he's not trying to hide at the side, even though we've made it downstage. But when the mirrors were covered, we managed to get him back into the center. So it was like, 'Okay, now you're downstage, but you're also center.' So that's really cool. So it's like, 'Okay, you're starting to get comfortable being right in the middle there.'

#### Conclusion

The results of this case study show that Miller has had many positive experiences with recreational dance. Most significantly, Miller's involvement with dance offers him connection to others through building supportive relationships and a sense of community. Miller's participation in dance also helps him develop and express his strengths, most notably his zest for life, kind-heartedness, sense of humour, independence, and ambition. Lastly, dance has a positive impact on Miller's sense of self; dance helps shape his self-confidence, provides him with positive social feedback, and offers a context through which he can overcome barriers and challenge stigmatization.

The findings from this case study indicate several themes that are significant to Miller's experiences with dance. The next chapter will begin by discussing five significant themes that have been addressed in chapter four. I believe these themes are most significant and are saturated across the data. Additionally, the results indicate noteworthy elements of Miller's involvement

with dance that positively inform his sense of self. The findings from this case study can also be applied to general leisure values as well as indicate implications to individuals with ID, recreational dance, therapeutic recreation, and research.

### **Chapter 5: Discussion**

The primary purpose of this case study was to develop an understanding of the lived experiences of an individual with an ID with community-based recreational dance. Second, this research sought to understand the ways that recreational dance impacts the sense of self for an individual with an ID. The literature review discussed the research published relevant to leisure, recreational dance, sense of self, and individuals with ID. Using a hermeneutic phenomenological lens, I sought out the findings from this study by exploring the lived experiences, thoughts, and perspectives of Miller and three other people who are significant in his life. This final chapter will present discussions and draw conclusions from the findings of this case study using a leisure lens. First, I will discuss the five overarching themes that were significant in the results. Second, I will explain the findings related to sense of self. Third, I will address significant leisure concepts that related to the results. Last, I will offer implications to the therapeutic recreation practice, recreational dance, and research as well as highlight the major lessons that I have learned from this research.

### **Themes**

The results presented many aspects of Miller's experiences with recreational dance.

Although all of the themes gathered from this research have been presented in chapter four, the following section will highlight five major themes, which have been outlined in chapter four, and discuss them in greater length. These five themes are strengths, relationships, belonging, confidence, and sexual energy.

## **Strengths**

Miller's experiences with recreational dance allowed him to nurture and capitalize on his character strengths. The results from this case study indicate that developing and expressing

strengths within Miller is significant for his well-being and an important benefit of his experiences with recreational dance. Miller strongly identifies with his strengths and employs them to foster a life well lived; Miller is an illustration of a strengths-based identity.

Over the past two decades, there has been a shift in the way helping professions approach working with people. Moving away from focusing on the problems and deficits of people, helping professionals are now encouraged to concentrate on their strengths instead (Biswas-Diener, 2010; Seligman, 2011). This paradigm shift is part of positive psychology, which was introduced by Martin E.P. Seligman in 1998 (Biswas-Deiner, 2010; Seligman, 2011).

Jones-Smith defines strength as "that which helps a person cope with life or that which makes life more fulfilling for oneself and others" (2016, p. 558). Strengths are innate character traits that generate positive emotion and beneficial results when employed. Seligman (2011) suggests that discovering and employing strengths helps build well-being. Emphasizing strengths in individuals with ID can create more inclusion by encouraging others to acknowledge their potential contributions and positive attributes as opposed to their deficits or limitations (Carter, Boehm, Biggs, Annandale, Taylor, Loock, & Liu, 2015). Focusing on the strengths of individuals with ID can result in helping to ensure that appropriate education, support, and services are provided to them as well as to those with whom they interact (Campbell, Milbourne, & Silverman, 2001). According to a recent study, focusing on the

strengths of youth with ID is the strongest contributor to psychological well-being, autonomy, and positive relations with parents and peers (Biggs & Carter, 2016). Highlighting strengths of people with ID, such as dedication and reliability, causes employment success, which is typically difficult to obtain among members of this population. Lastly, the literature

suggests that focusing on the strengths of youth within the ID population presents more opportunities for them, specifically in early adulthood (Carter et al, 2015).

In line with strengths-based perspectives, Miller has discovered his strengths and fosters them to live his best life. Miller's engagement with recreational dance plays a vital role in the cultivation of his strengths. In this way, dance has allowed him to continue to develop and express his strengths, which creates a positive spiral towards best living.

The literature explains that successful participation in recreational dance requires individuals to recruit and rely on specific strengths and skills (Zitomer, 2016). The specific aspects of recreational dance that encourage people to develop and express their strengths are limited in the literature and vary between individuals. One aspect specific to recreational dance that stimulates strengths expression can be through inclusive choreography. Block and Johnson (2011) have found that dance in a classroom setting, with an inclusive instructor, can allow each dancer's abilities to be woven into the choreography. This can allow dancers to be seen by their fellow classmates for their strengths, which is particularly valuable when teaching dancers with disabilities.

Other studies argue that recreational dance can support the cultivation of strengths, in a similar way to other leisure activities. Along with incorporating strengths into choreography, Block and Johnson (2011) argue that dance, like other leisure pursuits, can provide a sense of freedom and opportunity for creativity that can allow people to express themselves and their emotions. Another researcher suggests that dance, like other creative leisure pursuits, offers an emotional outlet as dance can be a form of communication for individuals with Down syndrome (Clark, 2011). The context for emotional expression that dance provides people may be another reason why dance encourages people to discover and express their personal strengths. Block and

Johnson (2011) explain that people with emotional disorders often mimic the behaviors of others in society; however, dance can offer an outlet for such individuals to express themselves on an individual basis, and thus self-knowledge and strengths-awareness can develop.

Perhaps it is the expressiveness of dance that encourages individuals to discover and express their strengths. With exception of the beneficial role of inclusive choreography, dance offers participants the opportunity to explore and capitalize on dancers' strengths if the leisure activity fits well with the interests, personality, and values of the individual. Even though dance has the benefits of choreography to showcase dancers' personal strengths, the literature indicates that any leisure pursuit that invites creative expression can facilitate the expression of strengths in participants. Individuals who are not interested in dance, will probably not experience the cultivation of strengths that Miller and others gain from dance. For Miller, because dance is an activity that suits his strengths, interests, and outlook, it allows him to express his strengths. Ultimately, it is the match between the leisure activity and the individual that can cultivate strengths.

# Relationships

Along with character strengths, recreational dance provides Miller with the context in which to build significant relationships. According to the literature, building supportive relationships and associated social skills can be achieved through leisure engagement (Caldwell, 2005; Hood & Carruthers, 2013; Stumbo & Peterson, 2009). Furthermore, building relationships is often done within leisure contexts, especially supportive relationships with peers and recreation staff within group leisure pursuits (Duerden, Taniguchi, & Widmer, 2012). Like other leisure endeavours, community-based dance programs offer individuals with ID the opportunities for socialization and social skill development (Becker & Drusing, 2010). Studies show that

recreational dance programs can reduce levels of social anxiety (Becker & Drusing, 2010) and develop communication skills (Reinders et al., 2015) for people with ID. Clark (2011) reveals that community dance programs support the development of social skills for dancers with ID partly by the use of teamwork when dancing with others, such as creating choreography in groups. In addition, Stark and Newton (2014) found that task-oriented environments where mastery, effort, and individual progression is encouraged are associated with increased quality and quantity of friendships. Furthermore, Block and Johnson (2011) indicate that participating in a group dance program can increase socialization and relationship building as it provides participants with shared experiences and emotions. For instance, many dancers would often discuss particularly challenging or enjoyable dance exercises or performance experience such as experiencing performance jitters or excitement, which can contribute to forming close relationships among dancers. Although recreational dance can help build relationships though team-work related to choreographic work, ultimately any leisure pursuit that involves others as well as shared experiences, goals, and emotions can help build relationships between individuals.

In addition to relationships with peers, Miller has also formed mentorship relationships with others, both as a mentor and a mentee. Having a positive role model for people, especially youth, can be beneficial as it can help imagine their personal potential and support them through their endeavours (Rhodes, 2002). More specifically, Kane (2014) argues mentorships within a dance setting are likely to form organically when younger and older dancers are brought together in a shared space. He explains that mentors within dance can help instill a sense of motivation, creativity, and skill building in dancers, which contributes to self-confidence. Kane (2014) adds that such mentorships within a dance context can transcend the dance setting and impact individuals throughout their lives. For both friendships and mentorships, dance, like other leisure

pursuits, can provide an ideal platform as it is a shared passion among dancers of different abilities and experiences. It is the common creative expression and mutual interests that can instil social bonds between dancers (Kane, 2014). Ultimately, it is the collaboration between two individuals, with common experiences and goals, in any leisure setting, that can help form mentorships between people.

## **Belonging**

In addition to character strengths and supportive relationships, another major theme of Miller's experiences with recreational dance is belonging. Dance engagements offer Miller a sense of belonging. According to the literature, leisure pursuits can foster social support networks, social identities (Hood & Carruthers, 2013; Stumbo & Peterson, 2009), community involvement (Caldwell, 2005) and a sense of belonging (Peperkamp, 2018). Similarly, Peperkamp (2018) suggests that leisure pursuits can provide people with a sense of place as well as a sense of community. Kleiber (1999) explains that leisure pursuits encourage natural connections with others with whom we may identify and share patterns of actions and rituals. Peperkamp (2018) found that sharing ritualized interactions that include rules, boundaries, mutual focus of attention and common emotional experience among people can provide a feeling of group solidarity and promote emotional connection and enthusiasm towards others.

More specifically, the literature presents the sense of belonging that individuals can gain from recreational dance experiences. Researchers argue that dance programs increase a sense of belonging among participants. Block and Johnson (2011) found that dance experiences can assist individuals with ID to develop a sense of social responsibility and offer opportunities to discover their value within a group context. Recreational dance classes require students to employ cooperative efforts through various aspects of dance classes (Block & Johnson, 2011), which

contributes to a sense of belonging (Kreutzmann, Zander, & Webster, 2018). For instance, collaborating with peers to create choreography and developing a sense of commitment and positive interdependency to achieve common goals can help create a sense of belonging for dancers (Block & Johnson, 2011; Kreutzmann, Zander, & Webster, 2018). Additionally, Reagans (2010) explains that if dance classes include a recital, it provides students opportunities to interact in different setting, which can support creating a sense of belonging for dancers. Lastly, researchers explain that group choreographed performances typically involve physical synchronization between the dancers, which has been shown to elicit perceptions of rapport among dancers and social connectedness (Miles, Nind, & Macrae, 2009). Although many group leisure activities can provide people with a sense of belonging, recreational dance can specifically help facilitate a sense of belonging for dancers through incorporating collaborative choreographic work and participation in recitals in various settings.

### Confidence

Another major aspect that was addressed in the findings from this case study is confidence. Miller's experiences with recreational dance helps him foster and express his self-esteem and confidence. Although some studies indicate that recreational dance can decrease self-esteem in people as they can feel awkward or fearful dancing in front of others, or concerned that dancing highlights their disabilities, other studies suggest that dance, where creativity is stressed, can increase self-esteem (Steinberg & Steinberg, 2016). Similarly, dance can help build confidence among people with ID (Oliver & Hearn, 2008). The literature reveals that dancers with disabilities can often feel empowered by learning and performing dance (Ashwill, 1992; Band et al., 2011; Whatley, 2007). Cone (2015) explains that this confidence partly stems from dancers commonly being exposed to the lesson that there are no limits to what they can do within

a dance context. Additionally, Reinders (2015) explains that dance can contribute to the confidence of people with ID as many recreational dance programs promote peer acceptance, like when dancers show support to their peers by clapping and cheering for them when given the opportunity to do so. Although many leisure activities can help develop confidence in people, the literature shows that the creativity and freedom for expression that is encouraged within recreational dance can help individuals build their self-confidence if dance is in line with one's interests and strengths. However, ultimately, any leisure pursuit that promotes creativity, self-expression, and appreciation and encouragement from others can contribute to people's self-esteem if an activity-fit is achieved.

# **Sexual Energy**

A final theme that became apparent in the results of this study was the sexual tension that Miller seemed to experience. This aspect of Miller's identity seemed to be met with a lack of opportunity to express his sexuality.

Like other human beings, people with ID are sexual beings who crave sexual and intimate experiences with others. Despite these normal and healthy needs, many people in healthcare professions neglect to understand, discuss, or even acknowledge their sexuality (Leutar & Mihokovic, 2007). Medina-Rico, Lopez-Ramos, and Quinonez (2018) show that many individuals view people with ID as asexual, fear viewing such individuals as sexual beings, younger than they are, and needing protection from sexual abuse. Other studies show that people misperceive individuals with ID as unable to understand the intricacies of sexuality or unable to comprehend sexual education (Graff, Moyher, Bair, Forster, Gordon, & Clem, 2018). Not only do these misconceptions negatively impact the sexual identity and impede on the sexual

experiences and opportunities for such individuals, but they also deprive their access to sexual education (Graff et al., 2018; Medina-Rico, Lopez-Ramos, & Quinonez, 2018).

Like most young men, Miller has a strong desire for sexual expression, which he often vocalizes. He is flirtatious to women, regularly expresses his desire to have a girlfriend or wife, and repeatedly described himself as a "hot guy" and "a ladies man". Despite Miller's glowing sexual identity, he is met with a limited opportunity for sexual experiences. Although his experiences with dance socials, such as his high school prom, allowed him to interact with women, it seems that Miller experiences tension between his self image as a sexual being and the way he is perceived by others as an asexual person. It appears this tension becomes expressed through his approach to dance. For example, Miller often shows off his dance moves to women and has "dance battles" with one of his friends at the end of dance class or at community socials. Perhaps once societal misconceptions about sexuality among people with ID are addressed and such individuals receive access to relevant and meaningful sexual education, Miller's desire for sexual intimacy will be addressed. Until then, perhaps dance will continue to be an outlet for the tension that seems to exist between Miller's sexuality and society's inability to recognize this aspect of him.

### **Sense of Self**

Forming a positive sense of self is important, especially among people with ID, who often face challenges and regularly experience adversities (Craven, Marsh, & Burnett, 2003). The literature demonstrates that leisure pursuits offer a context through which sense of self can be fostered (Kleiber, 1999). More specifically, the literature explores the ways that dance impacts the identity of people with disabilities. The self-expressive nature of dance provides individuals with different abilities the opportunities to affirm themselves as people who are

entitled to respect, access to rights and opportunities, and have unique abilities and talents (Harmon, 2015). Furthermore, the literature highlights that dance is seen by some individuals with disabilities as a safe space which can give them the power to shape their identity for themselves and others (Harmon, 2015). Although the findings did not touch upon these theories, the participants discussed other aspects of recreational dance that are significant in contributing to Miller's positive sense of self.

According to the findings from this case study, Miller has a positive sense of self, which is partly fostered through his recreational dance involvement. His experiences with community-based recreational dance contribute to his positive sense of self in three main ways: increases confidence, provides social feedback, and resists stigmatization and barriers.

### **Confidence Related to Sense of Self**

Miller's self-confidence plays a major role in the way he sees himself, and his experiences with dance positively contributed to his self-confidence and sense of self. Not only is confidence helpful in general, but the researchers argue that high levels of confidence and self-esteem can positively impact sense of self. According to Popovici and Buica-Belciu (2013), one of the major constructs on which sense of self is centred is self-esteem. In addition, developmental psychologist, Erik Erikson (1963) presents developing self-confidence as one of six factors that contribute to positive sense of self formation.

## **Social Feedback**

Recreational dance can also provide people with opportunities to be exposed to social feedback. According to Shavelson et al. (1976), sense of self is formed based on one's experience with and interpretations of one's environment as well as the attitudes of important people in one's life. In other words, understanding the attitudes of oneself from others can help

to develop a strong sense of self. Kleiber (1999) suggests that leisure activities can offer social experiences and provide people with opportunities to reflect on the perceptions and judgments of others. Furthermore, leisure pursuits can provide people with a context to engage in social comparison and performance feedback, which are significant to the process in shaping sense of self (Kleiber & Kirshnit, 1991; Mannell & Kleiber, 1997).

Recreational dance provides dancers with opportunities to not only create social networks with peer dancers, but also involves dancing in the company of others, often performing on display, which provides exposure to social feedback. Furthermore, recreational dance can often involve learning or choreographing with others, which can be a prime context to understand the ways in which others may feel towards someone. Lastly, like other expressive arts, the nature of dancing in the presence of others encourages dancers to bare themselves and be vulnerable to others, which offers an opportunity to receive social feedback and therefore aids in the formation of one's sense of self. Although other group leisure activities can foster social feedback, dance specifically can provide people with social feedback though the involvement of shared choreographic experiences and dancing and emoting in the presence of others.

The literature on social feedback explains that positive social feedback can have a positive impact on sense of self. Research indicates that active recreation can positively contribute to feeling valued by others (Boyce & Fleming-Castaldy, 2012), which the literature claims is an important element of creating a positive sense of self (Erikson, 1963). More specifically, Zitomer (2016) found that community dance experiences can promote peer acceptance for individuals with ID, which can support sense of self development.

For Miller, dance provides him with social feedback through his shared experiences with peers and allowing others to experience his creativity, emotional expression, and love of life

through his dancing. Consistent with the literature, because the feedback he receives from others was positive, it contributes to his positive sense of self.

# **Barriers and Stigmatization**

Recreational dance gives Miller opportunities to resist barriers and stigmatization, which may enhance his sense of self. The literature indicates that stigmatization towards people with ID can negatively impact sense of self among this population (Duvdevany, 2002; Huck, Kemp, & Carter, 2010; Popovici & Buica-Belciu, 2013). Studies indicate that people with ID have more negative sense of self when compared to people without ID (Datta, 2014). Many researchers argue that negative attitudes towards people with ID give such individuals the desire "to be seen as ordinary", which can impact the way people with ID construct or express their sense of self (Beart, Hardy, & Buchan, 2005; Dorozenko, Roberts, & Bishop, 2015). Furthermore, researchers explain that people with ID who engage in inclusive settings are more likely to form a more positive sense of self than those who function in segregated environments (Begley, 1999).

Coleman (1983) explains that inclusive settings allow for more opportunities for individuals with ID to feel like they are fulfilling general expectations. Dance experiences that integrated Miller into the community were important him and specifically seemed to positively contribute to his sense of self, which is conforms to the literature.

Studies have shown that leisure engagement can increase social acceptance and decrease stigmatization. For many individuals with disabilities and illnesses, social acceptance and freedom from stigmatization support the cultivation of a positive sense of self. The literature confirms the idea of social acceptance and reduced stigmatization through leisure pursuits (Lundberg, Taniguchi, McCormick, & Tibbs, 2011). Research findings also discuss the sense of normalcy that leisure experiences may bring to people's illnesses or disabilities (Lundberg et al.,

2011). More specifically, Ashwill (1992) found that dance can provide people with ID with a platform to gain access and equal rights to leisure pursuits as well as developing awareness and advocacy for the disability population.

Studies show that dance can also develop sense of self, self-acceptance, and self-love among people with ID. Harmon (2015) explains that dance can allow individuals with disabilities a context through which to form their sense of self as dance, particularly performance dance, provides opportunities for self-expression, self-affirmation, and presents such individuals as people with talent who are deserving of rights, opportunities, and respect. In this case study, although the participants did not address these aspects specifically, the participants discussed the value of dance classes providing Miller with dance skills and confidence, which seemed to have benefited his sense of self.

Along with a sense of competence, Block (2008) found that dance can generate the normalization of peoples' differences and abilities. Dance classes can provide an opportunity for the instructors and dance students to become familiar with both the strengths and weaknesses of each student. Often instructors build choreography based on the strengths of the dancers in the class, which offers a medium in which to showcase individuals' talents. This can provide people with different abilities with a sense of contribution to the choreography and dance class as well as have them be acknowledged for their strengths and abilities, thus including and normalizing everyone in a group (Block, 2008).

Although the participants did not specifically discuss the individual talents of each dancer in the dance classes, Kate described the attention she paid to Miller and other dancers' individual requests. She explained:

Quite often, he'll come to me and he'll be like, 'What about this song?' Or, 'I want to do this or try this.' So I try and incorporate some of the music he likes and some current stuff. He does like a lot of old music as well, but over the years, I've tried to be like, 'All right, you like Michael Jackson? Here's a Michael Jackson song, Miller. This one's for you, buddy.'

As suggested by the literature, the attention and acknowledgement that Kate provides Miller in his dance classes may highlight his interests, and ultimately may improve his sense of self. Kate also discussed the specific talents that Miller demonstrated in his dance classes, which may also contribute to his positive sense of self. She stated:

And he likes to show me his moves as well. So as much as I'm teaching him some moves, that if we have a water break or something, he'll be like, "Well, come on, look at my cool move like this." And I think making time for your students in class like that for them to have those moments where they can share something with you, so it's not always you dumping stuff on them, is key to a good back and forth relationship.

### Leisure

# The Leisure and Well-Being Model

Miller's experiences with dance demonstrates the beneficial role that leisure can have in people's lives. Miller's use of leisure to enhance his well-being is exemplary of the Leisure and Well-Being Model (LWM). Developed by Hood and Carruthers in 2007, the LWM reflects the current shift in healthcare from a deficits-based focus to a strengths-based perspective. One of the major ideas behind this shift is the research which supports that the reduction or elimination of deficits alone does not necessarily result in healthy and happy individuals and communities. Rather, while this model acknowledges the value in reducing deficits to enhance people's lives, it

also promotes the importance of cultivating and capitalizing on character strengths and abilities that can create healthy and happy people (Carruthers & Hood, 2007; Hood & Carruthers, 2007). The main goal of the LWM is "to directly facilitate the development of the contexts and experiences that increase positive emotion and the development of the resources and capacities that support well-being" (Carruthers & Hood, 2007, p. 280). The LWM is based on the idea that the nature and quality of an individual's leisure involvement can impact their sense of well-being. The LWM offers several ways to cultivate a satisfying leisure lifestyle. Miller's experiences with dance highlight three of these attributes of leisure: authentic leisure, leisure gratifications, and virtuous leisure.

**Authentic Leisure.** Although Miller regularly participates in other leisure pursuits, recreational dance plays a large role in his leisure lifestyle. Not only does Miller really enjoy dancing and takes many opportunities to dance, but also dance seems to be a satisfying leisure pursuit for Miller as it aligns with his values and attitudes. In many ways, dance is an authentic leisure pursuit for Miller.

Hood and Carruthers (2007) define authentic leisure as "the purposive selection of leisure involvement that is reflective of essential aspects of the self" (p. 312). Authentic leisure suggests that the value of leisure pursuits is in providing a context to help people come to know themselves better as well as to reflect and express their values, beliefs, and attitudes. Kleiber (1999) argued that leisure, when authentic to the individual, has the ability to allow an individual to explore his/her interests and capacities. Authentic leisure maintains the value in establishing a person-activity fit and suggests that leisure, when chosen freely and is congruent with one's sense of self, can enhance well-being (Sheldon & Lyubomirsky, 2004).

Miller is an illustration of authentic leisure; dance is a leisure pursuit that is congruent with his values, beliefs, and attitudes. For example, Miller has a love for life, which is evident through his dancing. Miller often dances on the front lawn outside his house. This dancing is improvised, free, and reflects his positive attitude and zest for life. In addition, dance is an authentic leisure pursuit for Miller as it complements his charismatic, confident, and boisterous personality. For instance, Gail describes that dance allows Miller to express his true self. Furthermore, Miller's dance participation is congruent with his fun and light approach to life. Miller values adding humour to life events and dance is a leisure pursuit which reinforces this value. Moreover, Miller's involvement with dance is reflects his value of belonging to a group. Lastly, dance is an authentic leisure pursuit for Miller as it expresses his value of inclusion and his belief that people deserve to have the opportunity to take part in all life domains without stigmatization or barriers. This was evident through the actions he took to allow himself to participate fully in a local parade.

Leisure Gratifications. Along with authentic leisure, leisure gratifications is another element of satisfying and constructive leisure that is presented in the LWM model. Leisure gratifications is based on Seligman's (2002) notion that although pleasure and positive emotion are important to achieving well-being, people want more than just feeling good; they also want to develop themselves towards a life of meaning and purpose. According to Seligman (2002), experiencing gratification requires one to develop and exercise personal strengths and values. In other words, Seligman argues that achieving a sense of gratification requires people to recruit their strengths and abilities to overcome challenges. Gratifying experiences often require people to be fully emerged and engaged in an activity, which is described by the theory of flow, which also contributes to the conceptual framework of leisure gratifications.

Developed by psychologist Mihalyi Csikszentmihalyi, flow is a theory which is based on the premise that happiness cannot be pursued independently, rather it is a result of one's personal dedication to a greater cause (Csikszentmihalyi, 1990). Flow, also known as optimal experiences, are exceptional moments in which we feel very alive, present, and focused (Anderson & Heyne, 2012). Within the flow state, individuals' attention becomes completely absorbed in the task; they might experience losing self-consciousness, track of time, and even the sense of their own thoughts and feelings (Seligman, 2011). As Seligman explains, flow occurs when one is engaged in an activity in which the challenges required to effectively complete the activity matches the skills and strengths that the engaged individual possesses (Adelaide Thinkers in Residence, 2012). Leisure pursuits provide an ideal context for flow to occur as they are voluntary, which can increase the probability that an activity will result in gratification (Anderson & Heyne, 2012; Kleiber, 1999). Therefore, the concept of flow is highly regarded in therapeutic recreation, where one of the goals is to support people's engagement in an activity, which often results in achieving a state of flow. Anderson and Heyne (2012) explain:

If the task is too simple, the participant is likely to lose interest or become bored. If the activity is too difficult, the participant may become frustrated or anxious. Somewhere along the fine line between these two levels of difficulty lies a 'flow channel' in which the person stretches his or her skills to meet the challenge of the activity (p. 113).

Csikszentmihalyi (1997) describes the ideal balance between challenge and skill where flow can occur in the following way: "When high challenges are matched with high skills, then the deep involvement that sets flow apart from ordinary life is likely to occur" (p. 30).

Research indicates that states of flow which are experiences through leisure seem to offer a space within which to develop a positive sense of self (Elkington, 2011). Elkington (2011)

argues that states of flow experienced in leisure are inherently intertwined with the essence of an individual. In other words, it is commonly during flow-like states that the true inner self of an individual can be revealed.

Considering the concept of flow, Hood and Carruthers (2007) define leisure gratifications as "leisure experiences that are optimally challenging and engaging, and that lead to sustained personal effort and commitment to the experience" (p. 314). In this way, gratifying leisure involves using one's skills to meet challenges in an engaging way, which contributes to personal development. One of the elements of leisure gratifications is the participation in leisure pursuits that can become increasing more challenging over time, which often results in a progression of skill development and contributes to a state of flow. Kane (2014) found that dance, when done in immersive and motivating environments, can help individuals achieve gratification and states of flow. Because dance provides a progression of challenge and skill, it can be an ideal leisure activity to experience gratification and flow.

Miller exemplifies leisure gratification through his participation in recreation dance. For example, in dance class, Miller engages in this practice to develop new skills, from which he can gain a sense of gratification. In addition, Miller's mother described the appropriate match between skill and challenge in leisure pursuits that is addressed in leisure gratifications. For example, when asked if she thought Miller might want to have more integrated dance opportunities, she explained that the integrated classes her son attends provide a good balance between challenge and enjoyment. Jody elaborated by explaining that if an activity, such as dance, does not have a balance between challenge and skill level, Miller would either lose interest or get frustrated and give up. Through dance, Miller has achieved a balance between skill and challenge, which has provided him with experiencing gratification and states of flow. As

Miller continues to dance, he will have the opportunity to undertake more challenges as his skills develop, and in turn, continue to skill build as challenges in dance present themselves to Miller.

**Virtuous Leisure.** Born from Seligman's (2002) notion that using one's strengths to serve something larger than the individual supports well-being, virtuous leisure acknowledges the value in using one's capacities to better the world. Carruthers and Hood (2007) define virtuous leisure as "the capacity to engage in leisure experiences that develop and/or mobilize personal strengths, capacities, interest and abilities in the service of something larger that oneself" (p. 316). Research has shown that leisure can be more fulfilling when it contributes to a sense of purpose or moral accomplishment (Wrzesniewski, Rozin, & Bennett, 2003). In addition, involvement in virtuous leisure pursuits has been known to increase community connection, sense of competence, and the number of interdependent relationships (Lyubomirsky, Sheldon, & Schkade, 2005). Most notably, volunteerism can be a leisure pursuit that would be considered virtuous in nature. Studies demonstrate that people with disabilities benefit from volunteering as it can increase confidence and social networks and help develop social skills, work-related skills and a sense of agency (Miller, Schleien, Brooke, Frisoli, & Brooks, 2005). More specifically, Miller et al. (2005) found that volunteer experiences can provide people with ID with enjoyment, an increased sense of purpose, and social connections. Along with volunteerism, developing interdependent relationships in leisure contexts can also be considered virtuous leisure as well (Carruthers & Hood, 2007; Hood & Carruthers, 2007).

Although Miller volunteers at a monthly youth dance in his community, this does not seem to be an ideal situation for Miller occupationally. Like most young adults, Miller would like to have full-time employment. Even though Miller benefits from this volunteer experience, this opportunity is not his desired outcome, rather used as a substitute for his lack of

employment. Miller's role as a mentor in his tap class reflects virtuous leisure. Through his supportive role towards one of the younger and newer dancers, Miller is able to use dance in a virtuous way, contributing to his overall sense of purpose, satisfaction, and well-being.

### **Serious Leisure**

Miller's involvement with recreational dance is exemplary of serious leisure. Serious leisure is:

The systematic pursuit of an amateur, hobbyist, or volunteer core activity that people find so substantial, interesting, and fulfilling that, in the typical case, they launch themselves on a (leisure) career centred on acquiring and expressing a combination of its special skills, knowledge, and experience (Stebbins, 2007, p. 5).

Serious leisure participants are often associated with their leisure pursuit with enduring involvement, unusual intensity, and considerable commitment (Jerry & Hwang, 2018). Stebbins (2001) presents six qualities found in people who are active in serious leisure, including perseverance, significant personal effort, and an identity which relates to the leisure activity. In addition, research shows that participating in serious leisure can offer personal and social benefits, such as contributing to self-expression, a sense of accomplishment, sense of self, social interaction, and sense of belonging (Stebbins, 2007). Stebbins (2001) argues that serious leisure often causes individuals to experience states of flow as one's engagement and commitment to serious leisure is immense.

Consistent with the literature on serious leisure, Miller benefits from pursuing dance in a serious leisure context. Miller's commitment to dance has allowed him to adopt the identity of being 'a dancer' within himself and among those around him. As such, Miller's deep and dynamic relationship with dance seems to benefit his sense of self and well-being.

# **Implications**

Among the various phenomena that are explored in this research, there is dissonance at play. Although the constructs in this study have been neatly described, there can be a messiness that exists for people in the dance and ID communities. For example, from my experience in the dance community, the physical demands that are placed on dancers, related to both their bodies and technical performance, can sometimes be at odds with the health and biology of dancers.

There is also messiness around the notion of dancers with disabilities. Like other athletes with disabilities, dancers with disabilities can sometimes be viewed as heroic, brave, or special for 'overcoming' their disability. Most people with disabilities to not want to receive praise for their daily pursuits or professions. This attitude towards people with disabilities can create an even wider divide between those with and without disabilities. In a different vein, when I tell people that I dance with individuals with ID, a common response is, "they can dance?". This attitude is at odds with dancers with ID, including Miller's experiences with dance and identity as a dancer. As an abled-bodied dancer, I acknowledge the limitations in my understanding of what it is like to be a dancer with an ID.

Additionally, there is tension that exists within the ID communities around inclusion, sexuality, and independence. There can be much dissonance that are caused by parental involvement in the lives of people with ID. For instance, from my experience working in the ID community, I often see dissonance between the needs of my clients and the desires of their parents. Sometimes this can manifest by client desires for romantic experiences with others and a lack of support from their parents towards fulfilling such needs. Tension can also exist from the ways in which guardians and support professionals view and treat people with ID, often undermining their child's or client's abilities to participate in the community. This attitude is

often an attempt to keep one's child or client safe in a world with people who can sometimes take advantage of vulnerable people. Although this reaction is understandable, not only can this attitude limit the opportunities of people with ID, but it can also cause people with ID to develop learned helplessness. The tensions that exist around ID stereotypes and the use of the word 'disability' are noteworthy as well. As an abled-bodied person, I can only understand these tensions to an extent, but I acknowledge that they can create dissonance and their influence is significant.

### **Individuals with Intellectual Disabilities**

The findings from this case study indicate that leisure, and its benefits, are no different for someone with a disability. Communities must adjust and accommodate to include and allow for full participation by everyone. People with ID are no different than the able-bodied; they have the same needs, desires, and dreams. As such, we must continue the process of deinstitutionalization and build a society that sheds its stigmatization and adjusts to provide access and opportunity for everyone. I believe this transition would be most effective, genuine, long-lasting, and just, if it were led by the individuals in this population. We must continue to offer platforms and encourage those with ID to share their experiences to help create communities that are truly accessible and inclusive. Like other studies indicate, almost all of Miller's challenges resulted from social constructs of disability. In other words, most of the barriers that Miller faced were not due to his diagnoses, but rather caused by stigmatization. I believe that an increase in meaningful participation in society from people with ID would increase awareness and knowledge about the strengths of individuals with ID and thus help create a stronger fabric of society.

Many people with ID experience barriers to satisfying and meaningful leisure activities. This study suggests that increasing access and opportunities for members of this population is necessary not only to create an inclusive society, but also to better the lives of everyone, regardless of ability.

### **Recreational Dance**

One of the challenges with researching dance experiences is putting dance, which is experiential and ephemeral, into words. For this research, I approached this task by using descriptive words. However, I acknowledge that describing dance in this way only offers a limited understanding of Miller's experiences with dance. Ultimately, it is only Miller who can truly understand what it is like to live his experiences.

This case study tells us that dance, when complementary with one's interests, strengths, values, and outlooks, can help build self-confidence, supportive relationships, a sense of belonging, and a sense of self.

On a more practical note, the findings indicate the importance for recreational dance environments to be inclusive, both physically and attitudinally, value diversity, and allow each dancer to participate communally and experience success (Kaufman, 2006). Zitomer (2017) outlines four constructs that reflects an inclusive dance education environment. First, an inclusive dance environment should involve mutual trust between dancers, which can be created through interdependent relationships and establishing respect for individuality and diversity and people's varying experiences and perspectives. Second, relational engagement should be sought when building inclusive dance programs. This occurs when people explore issues together and connect as a community. Third, embodiment addresses the awareness and appreciation that can be gained through moving bodies in a shared space. The very presence of bodies which have

been societally deemed as disabled can establish a sense of value towards such individuals and challenge what it means to dance. Finally, an inclusive dance environment must be exactly that; it must include every person as an integral contributing member of the community (Zitomer, 2017).

Based on this case study, it would be beneficial for recreational dance educators to focus on offering dancers with different abilities opportunities for collaboration and performance. As indicated by the literature, collaborating with other dancers, such as building choreography, as well as having common emotionally-charged experiences such as performing, can enhance the sense of belonging and social connections of dancers.

# **Therapeutic Recreation**

The findings from this case study imply that leisure is a domain of life that, when in line with one's interest, personality, and values, can positively contribute to one's quality of life. As understood by Miller's experiences with dance, leisure can develop and capitalize on strengths, increase self-confidence, sense of belonging, significant social connections, and a positive sense of self.

Strengths-based perspective. Historically, there has been an overwhelming focus on the deficits of people with ID, which has prevented such individuals from receiving support and experiencing inclusion (Campbell, Milbourne, & Silverman, 2001; Russo, 1999). Negative and exclusionary outcomes are not surprising when attention is mostly paid to the deficits of people as opposed to their strengths (Carter et al., 2015). Over the past two decades, there has been extensive research conducted in the area of strengths, which suggest that emphasizing and supporting character strengths within individuals with ID increases their well-being (Biggs & Carter, 2016; Russo, 1999).

Within the field of therapeutic recreation, there is endless opportunity to focus on building and fostering character strengths among people. Leisure and recreation are ideal contexts through which strengths can be established and nurtured. Many leisure pursuits require skills and talents that people may not use in other areas of life (Anderson & Heyne, 2012). It is beneficial for therapeutic recreation professionals to assess the strengths of each person and ensure that leisure opportunities, resources, and environments capitalize on and enhance such strengths (Anderson & Heyne, 2012).

Strengths can be discovered through self-examination and self-reflection; however, strengths can also be discovered through the support of another person, such as a therapeutic recreation professional. Through interaction with those we serve, practitioners can enhance strengths discovery using observation skills, specific questioning, strengths scales, questionnaires, and other self-reflective exercises (Jones-Smith, 2016). For individuals with ID, practitioners can also discover strengths through discussions with those who are close to the individual, such as a parent or support worker (Carter, et al., 2015).

There are several methods used to discover the strengths of individuals with ID. First, questionnaires are often used to measure strengths. For instance, the Assessment Scale for Positive Character Traits – Developmental Disabilities (ASPeCT-DD) developed by Woodard is a scale intended for parents and caregivers of individuals with ID to measure strengths within their child or client (as cited in Carter et al., 2015, p. 105). Additionally, questionnaires that are used in populations without ID would often be adapted for the use of individuals with IDD (Russo, 1999). Second, direct and indirect questioning are often employed to measure strengths of individuals within the ID population. Similar to populations without ID, such investigations will include "miracle" questions, "exception-finding" questions, "scaling" questions, and

"coping" questions. If such questioning would be directed at individuals with ID themselves, they might be adapted to accommodate individuals with lower cognitive functioning. Such adaptions might include using role-playing or using visual aids. Lastly, support staff who observe non-verbal communication of individuals with ID, such as body language and facial expressions, can be helpful in discovering strengths as well (Russo, 1999).

The results from this case study indicate the value of therapeutic recreation services adopting a strengths-based approach to the practice. According to Anderson and Heyne (2012), once the character strengths of an individual have been established, these traits should help guide the plans for that individual. In other words, the program plans should be built around the specific strengths of each client.

Identity development. Supporting the development of self-acceptance, self-esteem, and a sense of self is considered a goal in therapeutic recreation services (Coyle, Kinney, Riley, & Shank, 1991). Phoenix (2001) advocates for the use of identity theories to guide the facilitation of identity development in the therapeutic recreation practice. Depending on client goals, she suggests that practitioners can support individuals with values clarification and use leisure to support such values. For instance, Murray (1997) describes journaling to be an effective modality for identity development as it allows people to reflect and express their thoughts, ideas, beliefs, and future goals, which can help facilitate identity development. When supporting people who have acquired major injuries, such as a traumatic brain injury or spinal chord injury, Phoenix (2001) asserts the need to work with such individuals to help them reimagine a new identity after enduring a life-altering transformation, while finding ways to continue their previous leisure pursuits with any adaptation and/or exploring new leisure interests.

Authentic leisure. As explained in the previous section, one of the reasons dance experiences contribute to Miller's sense of well-being is because dance reflects his beliefs, values, and attitudes. In therapeutic recreation, establishing leisure preferences that are authentic and congruent with one's self-identity will enhance a sense of well-being in clients (Hood & Carruthers, 2007). In order for individuals to make informed leisure decisions, it is important that they are supported as needed through the development of self-awareness, be given opportunities to explore interests, and establish and express significant values and ideals. In this way, not only can leisure enhance one's values and beliefs, but it can also contribute to one's self-discovery (Hood & Carruthers, 2007). Lastly, the findings from this case study suggest the need for leisure pursuits to be individualized. Although costlier, this study demonstrates the value of leisure pursuits being selected based on the interests, values, and attitudes of the individual.

Authentic leisure is highly individual and therefore will vary immensely between people. For Miller, dance is a leisure pursuit that reflects his preferences, personality, and outlook on life. Many positive impacts that Miller experiences from dance can be gained by others through different leisure activities. Although this case study focuses on dance, the benefits that Miller gained through dance can also be achieved through other leisure activities as well. Therefore, many of the findings from this case study, can potentially be applied to other individuals and other leisure endeavours.

Leisure gratifications. The findings from this case study demonstrate that engaging in optimally challenging and engaging leisure pursuits can cause a sense of gratification for an individual. Within the therapeutic recreation practice, this case study indicates the need for ensuring leisure pursuits are gratifying for an individual. Accordingly, it is important to ensure that leisure activities should be adapted to meet the skill levels of clients and ensure a

constructive activity skill fit is achieved. The findings from this case study stress the importance of educating clients about the concept of flow and supporting them to create a balance between skill and challenge in an activity. Empowering clients to adapt the activity to their skill level or increase their skills and capacities to compliment the level of challenge in the activity will help individuals achieve a sense of flow independently (Hood & Carruthers, 2007).

Virtuous leisure. Therapeutic recreation professionals can help facilitate the skills related to volunteerism and developing interdependent relationships through leisure.

Furthermore, not only can practitioners increase awareness and opportunities for volunteer experiences, but they can also work to reduce stigmatization and barriers to accommodate individuals during their volunteer experience. Practitioners should also ensure that volunteer experiences complement the strengths, capacities, values, and interests of the individual. Lastly, facilitating mentorships between volunteers and others will likely create personal growth, community connection, and promote mutual respect, diversity, and inclusion.

Community integration. For Miller, some of his best moments with dance came as a result of participating fully in community events. The results from this study indicate the benefits of participating in leisure pursuits that are integrated in the community. Although the practice of therapeutic recreation involves and promotes community integration, this study argues that more work in this area remains to be done. Along with other professionals, it is part of the role of therapeutic recreation practitioners to seek out various avenues that integrate individuals with disabilities into the fabric of society and advocate for accessibility, acceptance, and accommodation for people with unique abilities (Stumbo, Wilder, Zahl, DeVries, Pegg, Greenwood, & Ross, 2015).

Findings such as this case study indicate that therapeutic recreation services for people with developmental disabilities must shift their approach with community integration. Many programs for people with developmental disabilities approach community integration though going on 'outings' into the community, such as sports games or amusement parks (Stumbo et al., 2015). While these experiences are valuable, this study demonstrates a need for community integration to involve more participatory experiences in a functional and meaningful way. Equipping individual clients with functional and independence skills to use in the community that meet their interests and strengths allows this population to truly participate in the community in an impactful and meaningful way.

This case study contributes to the evidence for the presence of therapeutic recreation professionals in community settings. These findings echo previous studies that suggest the need for therapeutic recreation to be practiced in the community where many clients go to school, go to work, and live their lives, to help create genuine integration within the community (Stumbo et al., 2015). The literature reveals that therapeutic recreation is particularly beneficial in schools where it is currently underrepresented. Shultz, Wozencroft, and Cihak (2017) found that having more therapeutic recreation practitioners work in the education setting to help reduce stigmatization and barriers faced by students with disabilities can contribute to the well-being of individuals with different in adulthood. Furthermore, studies highlight the need for post-secondary therapeutic recreation programs to better equip their students to serve people in a multitude of community settings (Shultz, Wozencroft, & Cihak, 2017).

The identity, role, and approach to therapeutic recreation has been under question, often dividing practitioners into differing schools of thought. It has been discussed whether this contested field falls within medicine, adaptive recreation, leisure, or some combination of these

three areas (Sylvester, 2015). Among the shift from medical models to social and ecological models, including critical disability theory, is the impact on therapeutic recreation and its approach towards supporting the full inclusion of people with disabilities across the scope of leisure and recreation. Mobily, Rodney, and Dieser (2018) argue that many therapeutic recreation professionals, especially those in hospital and healthcare settings, currently put forth almost all of their energy towards trying to reduce the impairments of clients and not enough effort towards facilitating changes in the environment, which are the predominate cause for most of the barriers to such individuals' leisure experiences.

In a similar light, several researchers in the field insist that individuals with disabilities do not specifically need therapy, rather they deserve access to leisure experiences like those of people without disabilities (Mobily, Rodney, & Dieser, 2018). In this way, scholars advocate for the training and education of therapeutic recreation professionals to focus less on rehabilitating individuals to appropriately engage in leisure activities, and instead pay more attention to managing the environmental factors which exclude some individuals from full participation. This approach is arguably in opposition to the concept of therapy in that it looks to alter the environment to support the individual instead of an individual having to change to fit the environment. One way to facilitate this approach is through the way that assessments are carried out. For example, Pedlar, Hornibrook, and Haasen (2001) suggest that client assessments should be less structured and take the form of open communication and interaction between the practitioner and the individual.

Although the need for access to satisfying and impactful leisure for everyone is clear, the role of therapeutic recreation is currently up for debate. Based on this case study, it is clear that meaningful community integration moves away from institutionalization and is a necessary step

towards full and genuine integration and equality. With this lens, I believe therapeutic recreation is most effective in facilitating community integration from within community spaces. To illustrate this approach, Sylvester (2015) states:

Therapeutic recreation becomes a freer space by shifting from a clinical to a political practice. In the process, therapeutic recreation discards the 'white coat' for leisure better suited for resisting stigmatization and discrimination and for reclaiming respect, dignity, and relational autonomy and self-determination (p. 186).

### **Future Research**

There are various possible directions for future research. Each set of findings can be further explored. For example, there is still research to be conducted on the ways in which strengths can be discovered and facilitated among people with ID. As well, the concept of self-esteem and relationships among individuals with ID can be studied further. Moreover, conducting research on the success of current community integration efforts might enhance both therapeutic recreation services and integration of people with ID. Exploring more methods of effective, meaningful, and functional community inclusion and participation will allow therapeutic recreation services to better reflect the needs of people with disabilities.

The sense of self among people with ID requires further research. This case study explored the various concepts related to sense of self in an individual with Down syndrome; however the ways in which these concepts related to Miller's sense of self were not explored. Further research must be conducted to understand the ways in which such concepts impact the sense of self in individuals with ID. As an abstract concept, sense of self can be a difficult construct for some to comprehend. Developing ways to communicate sense of self to people with

varying cognitive and comprehension abilities would be beneficial in furthering the literature on the sense of self among individuals with ID.

Lastly, continuing to include individuals with ID in the research arena is vital in understanding their experiences and ultimately improving their lives and the lives of those around them. We must continue to amplify the voices of people with ID as only they can most effectively and accurately educate people without ID of their needs. I believe once we decide to shine a brighter light on the lived experiences, thoughts, and opinions of people with disabilities, only then can we effectively serve all members of society, regardless of ability, and finally create communities that integrate people with varying abilities in a genuine and meaningful way.

### **Lessons Learned**

Although I had prior experience working with individuals with ID, this was my first opportunity to conduct research regarding people with ID and I gained many valuable lessons from this research. When I was reviewing the literature for this study, I was disturbed by the lack of participation from individuals with ID. There were many studies which explored the lived experiences of one or more individual(s) with ID; however, in all cases, they were accompanied by contributing perspectives from significant people in these people's lives. Eager to conduct a study that would only be based on the participation of people with ID, I confidently set out to find three participants who would share their experiences with me. After struggling to obtain three participants who were able to effectively participate in my study, I began to realize why many past studies on the experiences of people with ID involve the perspectives of guardians, care-givers, and support staff as well. There were various factors which resulted in this research study exploring the experiences of three dancers with ID becoming a case study about one dancer with ID.

For many people with ID, abstract concepts can be challenging to grasp and communicate. Although I adapted the language I used when referring to concepts such as sense of self, I quickly learned that verbally communicating these abstract constructs would prove to be very challenging. As addressed in the previous section, further research on conducting qualitative studies with people with ID is required.

Obtaining participants was also challenging due to reluctance from the guardians of eligible participants. Although some parents were willing to offer consent to have their child participate in the study even though they explained that their child would not be able to provide reliable or relevant information, many parents were not. Throughout participant selection for this case study, I met with parents who were hesitant to allow their son or daughter to be involved with research. Several parents did not permit their child to participate in this study as they explained that their child is unable to discuss abstract concepts. I was surprised to be met with such reluctance, although once I began to conduct interviews, I soon understood what many of these parents were trying to communicate. Despite many parents' accurate description of their child's abilities, some of the parents declined for the same reason, although their child seemed to be able to comprehend and articulate effectively. Therefore, although much hesitation from the parents of eligible participants was an accurate reflection of their child's abilities, I encountered reluctance from a few parents notwithstanding their child's strong communication and comprehension skills. Lastly, a few parents expressed their concern towards some of the interview questions that involved potentially difficult discussion matter, such as their disability and challenges. One of these parents agreed to have her daughter participate in the study under the condition that such questions would be omitted from the interviews. This taught me the level

of involvement and protection that some families adopt. Acknowledging that I am not a parent, this approach made me consider the differing ways people approach parenting children with ID.

Lastly, this research process taught me how to effectively interview. During the first interview, I realized that I would have to press harder and dig deeper to access the rich responses that I was seeking to obtain. Typically, I try to avoid asking people whom I do not know well, potentially emotionally charged questions. I learned that interviewers must go beyond these norms and boundaries. I realized that interviewing requires more than simply reading questions from a script; interviewing, especially those with differing cognitive abilities, is both an art and a skill that requires confidence and patience. Additionally, I learned that, provided I have consent, it is acceptable to ask difficult questions. Furthermore, especially when interviewing people with varying cognitive and comprehension skills, it is imperative to be creative and flexible throughout the interview to acquire meaningful data and make the interview most worthwhile.

# Conclusion

This case study presented the experiences of recreational dance for an individual with ID.

This research also offered insight on the ways in which dance impacted this individual's sense of self. The intention of this case study was to understand the role that dance plays for an individual. Therefore, although the findings are not generalizable, this study offers an in-depth account of the lived experiences and perspectives of one individual and his significant others.

This case study contributes to the growing body of literature in therapeutic recreation, developmental disabilities, and integrated dance. This research presented key findings which can strengthen the therapeutic recreation profession, improve the lives of individuals with ID, and help facilitate more inclusive communities.

Miller's experiences with dance were highly positive mainly because dance is the right leisure activity for Miller as it is compatible with his values, strengths, and personality. By achieving congruence among one's leisure pursuits and values and character, leisure can help generate social connections, character strengths, personal growth, and a positive sense of self. Although it is dance that contributes to Miller's well-being, any leisure pursuit, when chosen authentically, can help develop the self and improve well-being.

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## Appendix A



March 9, 2018

Brock University
Department of Recreation and Leisure Studies

St. Catharines, Ontario, Canada L2S 3A1 (905) 688-5550 Ext. 3259

## LETTER OF REQUEST TO ASSIST IN RESEARCH STUDY

**Project Title:** Identities in motion: An exploration of dance and sense of self among individuals with intellectual disabilities

Dear Program Directors,

For my Master of Arts degree in Applied Health Sciences specializing in Recreation and Leisure Studies at Brock University, I will be conducting a research study research that will explore the experiences of dance among individuals with intellectual disabilities. The study is entitled "Identities in motion: An exploration of dance and sense of self among individuals with intellectual disabilities". I am writing to you to request your help with accessing participants for this study.

Past research shows that dance, along with other leisure pursuits, can provide many benefits to quality of life and help people live well. This research project will aim to understand the experiences of individuals with intellectual disabilities with recreational dance. Further, I hope to explore the ways, if any, that dance impacts the sense of self among people with intellectual disabilities.

Eligible participants are individuals who are currently enrolled in a community-based recreational dance program, identify as having a diagnosis of mild or moderate intellectual disability, proficient in verbal communication, and at least 18 years of age. Participation in this study will involve participating in three short interviews inquiring about their experiences with dance and sense of self. To support recall ability, participants' dancing will be photographed and/or video taped during a dance class.

Data collection with each participant will only begin once I have received a signed informed consent form, which will outline the risks and benefits related to this project. Based on your program's protocols or preferences, participation in this study may require consent from guardians or advocates in addition to that from participants. In addition, this study will adhere to any research participation protocols that are required by The Dance Ability Movement. Last, the research process will only begin once I have received ethical approval from the Research Ethics Board at Brock University.

This study is not intended to cause any harm for participants, however sharing personal experiences may cause individuals feelings of distress. If any feelings of distress come up for participants, I will offer coping strategies with anxiety or distress during the interviews, as well as provide contact information to support participants who may experience distress following the interviews.

Participation in this study will provide individuals with an opportunity to reflect on and share their experiences and thoughts with others and potentially establish meaningful discoveries about themselves. Participant responses will also contribute to the growing body of research on integrated dance and intellectual disabilities, which may ultimately enhance future services and opportunities for individuals with disabilities. Furthermore, participation in this study will contribute to the body of research that exposes the voices and lived experiences of individuals with intellectual disabilities. Participants will receive a \$25.00 Tim Horton's gift card as an honorarium for their contribution to this research study.

As two of the few leaders in integrated dance in Ontario, I hope you will consider supporting me in obtaining participants for my research study. As a dancer and support worker for people with developmental disabilities, I am not only passionate about both areas, but I believe further research of this kind can ultimately benefit both dance and people with all abilities.

If you would like any further information about this research study, please contact me or my research supervisor (contact information below).

Thank you for your time and consideration.

Sincerely,

**Emily Harris** 

## **Student Principal Investigator:**

Emily Harris Graduate Student Department of Applied Health Sciences Brock University (647) 278-5078 eh15hq@brocku.ca

### **Faculty Supervisor:**

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## Appendix B

### LETTER OF APPROVAL

Sent: Wednesday, March 14, 2018 2:37 PM

**To:** Emily Harris

Subject: Letter of Approval

March 12, 2018

RE: Letter of Approval

To the Research Ethics Board at Brock University:

Emily Harris has requested our assistance with recruiting appropriate participants for her research study through our program during the months of April and/or May 2018. We have agreed to act as gatekeepers for this project and support Emily during in the several ways.

First, we will allow her to put up flyers and send out e-mails regarding recruiting eligible participants for her project, as well as possibly have her come to a couple of our host studios and introduce the study to our dancers.

Second, if participants provide us with consent to speak with Emily, we will help inform Emily on the decision-making abilities, communication preferences, and any note-worthy characteristics of each participant to help her receive informed consent and work respectfully and effectively with each participant.

Third, we will allow Emily, with participant consent, to take photographs and videos of the participants dancing during a class to help facilitate the participants' responses during interviews.

Fourth, we will allow Emily to interview the participants prior to or following the participants' dance classes at their host dance studio. Last, we will assist with providing space in the respective host studios for Emily to disseminate the research results to the participants.

## Appendix C

March 20, 2018

#### INTRODUCTION SESSION SCRIPT

(10 minutes)

### **Hello Everyone!**

My name is Emily Harris and I am a student and Brock University. I will be talking with you for the next 10 minutes about an opportunity to be involved with a research project. You can ask any questions that come up for you! Thank you for letting me speak with you today.

In my school, I am learning about recreation and leisure and I am working on a project that is teaching me about different experiences with dance. I am looking to talk with dancers who take dance classes and have unique abilities. I would like to understand how people with challenges with certain skills experience dance. I also want to know how people with different abilities who are involved with dance feel about themselves. If you think you will be able to help me with this project, I would love to hear from you!

Participating in this project will involve me taking pictures and videos of you during a dance class to help show you how you feel about dance. You will get to keep these pictures and videos. Participation will also involve being part of interviews. An interview is a discussion or conversation between to people, usually involving one person asking questions about a topic and the other person answering. For my project, you will participate in two interviews, about 30 minutes each, lead by myself. During the interviews, I will ask you questions about your experiences and feelings towards dance and yourself. You will use the pictures and videos that I took of you during the dance class to help you think of your ideas and feelings about dance. During the interviews, you can take breaks or stop any time you want, and you can share as much or as little information as you want.

After the interviews, I will make a summary about your feelings towards dance. Then, I will meet with you again and we will go over your answers to my questions from the interviews to make sure what I said about your experiences is correct. The interviews will be audio-recorded so I can remember what you said as I will be writing a report at the end of the project that will present your feelings about dance and yourself.

Participating in this project will give you the chance to share your stories, experiences, and ideas of dance and your life. Also, your participation in this research project will help people understand more about dance and people with different abilities. Finally, participating may also help create more places like Dance Ability in the future.

Helping me with this project will probably not cause you any harm, but there is a chance that people might find out that you are involved in this project. This may cause you to lose some privacy, which may make you feel uncomfortable. To help protect your identity, I will use fake names in the written report. Also, when I take pictures of you during class, I will also act that I am not only taking pictures and videos of you.

By participating in this project, you will receive a \$25.00 Tim Horton's gift card as a 'thank you' for your help with my project.

Does anyone have any questions about participating in my project?

\*\*\*Hand out letter of invitation\*\*\*

If you have any questions that come up later, I will be available to chat with after this class, or you can call or email me. If you are interested in participating in this research project, please tell me, your dance teacher or program director and we will help you with the next steps.

Thank you for listening and thinking about helping me with project!

## **SUPPORTIVE IMAGES**



Dance



**Dance class** 



Taking pictures and videos



**Dance pictures** 





Interview

## Appendix D



April 17, 2018

Dear Dance Ability Dancer,

## You are invited to participate in a research project!

### Who Am I?



My name is Emily Harris and I am a student at Brock University. For my Master of Arts degree, I am doing a project on dance and people with unique abilities. I will be getting help from my supervisor, Dr. Colleen Hood, who is a professor at Brock University. In order to learn about dance and people with various abilities, your dance program directors have agreed to help me find people who want to teach me about their experiences with dance.

### What is Involved?

In order to participate in my project, you must be taking recreational dance classes, identify as having unique abilities, be able to have conversations verbally, and be 18 years of age or older.

Participation in my project, involves participating in two interviews. The interviews will involve me asking you questions about your experiences with dance and life in general. The interviews will happen either before or after two separate dance classes. The interviews will probably be at the dance studio and will take about 30 minutes each. During the interviews, you can take breaks or stop any time you want. During the interviews, you can tell me as much or as little as you want. If you want, you can have a parent join us for the interview.

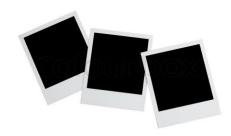




A few weeks after the interviews, you will meet with me again for about 15 minutes. During this meeting, I will show you a few words and sentences that talk about what you said during the interviews. This will help you make sure that I said what you wanted to say in the interviews and add or change anything you want. You will be able to take these summaries home. A few weeks later, I will write a report that will talk about your experiences with dance and the ways you see yourself.

To help us talk about your dancing, with your permission, I will take pictures and videos of you dancing during a dance class before the first interview. You will be able to keep these pictures and videos.





By participating in this project, you will receive a \$25.00 Tim Horton's gift card as a 'thank you' for your help with my project.



# Why Participate?

Participating in this project will give you the chance to share your stories, experiences, and ideas of dance and your lives. Also, your participation in this research project will help people understand more about dance and people with unique abilities. Finally, participating in this project may also help create more inclusive dance opportunities in the future.

### What are the Risks?

Helping me with this project will probably not cause you any harm, but there is a chance that people might find out that you are involved in this project. This may cause you to lose some privacy, which may make you feel uncomfortable. To help protect your identity, I will use fake names in the written report. Also, when I take pictures of you during class, I will also act that I am not only taking pictures and videos of you.

\_\_\_\_\_

If you have any questions, or would like more information about my research project, please call or email me, Emily Harris, or my supervisor, Dr. Colleen Hood. Our phone numbers and email addresses are written below.

If you are interested in participating in this research project, please tell me, your dance teacher or program director, and we will help you with the next steps.

Thank you for reading this letter and for thinking about participating in this project!



Sincerely,

**Emily Harris** 

Tharries

**Student Researcher:** 

Emily Harris
Brock University

Phone #: (647) 278-5078

Email: eh15hq@brocku.ca

**Supervisor:** 

Dr. Colleen Hood Brock University

Phone #: (905) 688-5550 Extension 5120

Email: chood@brocku.ca

## Appendix E



April 18, 2018

Brock University
Department of Recreation and Leisure Studies

St. Catharines, Ontario, Canada L2S 3A1 (905) 688-5550 Ext. 3259

### **GUARDIAN LETTER OF INVITATION**

**Project Title:** Identities in motion: An exploration of dance and sense of self among individuals with intellectual disabilities

Dear Guardian/Advocate,

My name is Emily Harris and I am a graduate student in the department of Applied Health Sciences, specializing in Recreation and Leisure Studies, at Brock University. For my Master of Arts degree, I am currently conducting a research study which will explore the experiences of dance among individuals with unique challenges. The study is entitled "Identities in motion: An exploration of dance and sense of self among individuals with intellectual disabilities". This research study is under the supervision of Dr. Colleen Hood, a professor at Brock University. Your dance program directors have agreed to help me access eligible participants who may be interested in participating in this study. I am writing to you either because your child/client has expressed interest in participating in this research and requires your consent to participate in this study, or to inquire about you child's/client's potential interest in participating in this research.

Past research shows that dance, along with other leisure pursuits, can provide many benefits to quality of life and help people live well. This study will aim to understand the experiences of individuals with unique abilities with recreational dance. Further, I hope to explore the ways, if any, that dance impacts the sense of self among people with different abilities and challenges.

Eligible participants are individuals who are currently enrolled in a recreational dance class, identify as having a diagnosis of intellectual disability, are capable of verbal communication, and are at least 18 years of age.

Participation in this study will involve your child/client's participation in two short interviews that I will lead. The interviews will take place at your child's/client's dance studio either before or after two different Dance Ability classes. The interviews will take approximately 30 minutes each; however, participants are able to take breaks or end the interviews at any point. The interviews will inquire about their experiences with dance and their sense of self. Participants will receive the interview questions prior to both interviews and are encouraged to share as much or as little information as they wish. Furthermore, the interviews will be conversational in nature and will incorporate a variety of techniques and tools to help facilitate relevant dialogue, such as

discussing pictures and/or videos of their dancing and using visual art as a means of expression. Provided participant verbal consent, guardians or advocates can be present during the interviews and provide assistance with comprehension and communication, if necessary.

In order to acquire pictures and videos of the participants' dancing, with the consent of all individuals involved, I will take photographs and videos of each participant during a dance class to give to the participants and to help facilitate conversations about their experiences with dance. Participants will also be encouraged to bring photographs and videos to the interviews to help guide the dialogue.

Following the interviews, summaries of the information that I gather will be given to the participants to check for accuracy and to possibly provide clarification. These will take the form of basic paragraph and the major themes will be displayed in a word cloud.

Participants will receive a \$25.00 Tim Horton's gift card as an honorarium for participating in this study.

Participation in this study will provide individuals with an opportunity to reflect on and share their experiences and thoughts about dance and themselves, as well as with potentially establish meaningful discoveries about themselves and/or their experiences with dance. In addition, participants may also benefit from receiving images and/or videos of themselves in a dance class. Similarly, participants may benefit from receiving a summary and word cloud on their unique experiences with dance. Participants will also contribute to the growing body of research on integrated dance, intellectual disability, and the self. This contribution may ultimately provide new insights, improve the quality of dance and other recreational programs, and increase the amount of such opportunities that are inclusive and accessible for individuals with disabilities.

This study is not intended to cause any harm, however, like all research that involves people, if a participant's identity in this study becomes known to others, there can be social repercussions, such as a loss of privacy or an impacted reputation. To reduce this risk, I will use pseudonyms when referring to each participant in the written report as well as refrain from including identifying information about the participants or the dance program. Furthermore, during the documentation of the participants' dancing, I will avoid concentrating my focus only on the participants, which will reduce identifying the participants from other dancers in the class. I will also rely on the 'zoom' feature on the camera to allow me to document the participants' dancing, while not needing to be close to the participant, which will aid in masking their identity as well. Additionally, the interviews and member checking sessions will be held in a relatively secluded space, yet not completely secluded to protect those involved in the interview.

In order for individuals to participate in my study, they will need to sign an informed consent form. All participation information for this study, including the associated risk and benefits, will be clearly explained, both verbally and in writing, to each participant and comprehension of this information will be assessed prior to participation.

This study has been reviewed and received ethics clearance through the Brock University Research Ethics Board (file #17-351).

If you would like any further information about my research study, or might be able to refer potential participants, please do not hesitate to contact me or my research supervisor (contact information below). If your child/client has expressed interest in participating in this research project and you consent to their participation, please inquire about or refer to the 'Guardian Informed Consent Form'.

Thank you for your time and consideration.

Sincerely,

**Emily Harris** 

Ehadis

**Student Principal Investigator:** 

Emily Harris Recreation and Leisure Studies Brock University (647) 278-5078 eh15hq@brocku.ca **Faculty Supervisor:** 

Dr. Colleen Hood Recreation and Leisure Studies Brock University (905) 688-5550 Ext. 5120 chood@brocku.ca

**Emily Harris, B.A.** has over six years of education and volunteer and work experience with individuals with developmental disabilities. She has experience communicating and supporting individuals with a wide range of interests, personalities, behaviors, abilities and communication styles. She is trained in Nonviolent Crisis Intervention® from Crisis Prevention Institute© and is working towards receiving the Certified Therapeutic Recreation Specialist (CTRS) certification from the National Council for Therapeutic Recreation Certification (NCTRC).

#### Appendix F



April 19, 2018

#### PARTICIPANT INFORMED CONSENT FORM

**Project Title:** Identities in motion: An exploration of dance and sense of self among individuals with intellectual disabilities

#### **Student Researcher:**

Emily Harris
Brock University

Phone #: (647) 278-5078 Email: eh15hq@brocku.ca

## **Supervisor:**

Dr. Colleen Hood Brock University

Phone #: (905) 688-5550 Extension 5120

Email: chood@brocku.ca

#### **INVITATION**

You are invited to participate in a research project. The purpose of this project is to learn about the experiences of people with unique abilities and dance. This project aims to understand the dance experiences of people with challenges with learning.



#### WHAT IS INVOLVED

To participate in this study, you will be photographed and filmed during a dance class by the researcher. You will be able to view and keep these pictures and videos and use them as a tool to help you think about your experiences with dance. You will also be encouraged to bring any dance pictures or videos you may have to help talk about your experiences with dance as well.

You will participate in two interviews, which will involve the researcher asking you questions about your experiences and feelings towards dance and yourself. The interviews will happen at the dance studio either before or after two separate

dance classes. Each interview will be about 30 minutes and will be audio-recorded for the researcher to create a written report of the project. The interview questions will ask about the ways that you feel about dance and yourself. You will receive the interview questions before the interviews take place. During the interviews, you can share as much or as little information, stories, and ideas as you wish and there are no right or wrong answers. If you want, you can have a parent join us for the interview.

A few weeks after the interviews, you will meet with me again for about 15 minutes. During this meeting, I will show you a few words and sentences that talk about what you said during the interviews. This will help you make sure that I said what you wanted to say in the interviews and add or change anything you want. You will be able to take these summaries home.

#### WHAT YOU MAY RISK

Helping me with this project will probably not cause you any harm, but there is a chance that people might find out that you are involved in this project. This may cause you to lose some privacy, which may make you feel uncomfortable.

To protect your identity, the information that you share will not be shared by anyone other than Emily Harris, Dr. Colleen Hood, and the research team. The ideas you share in the interviews may be written in the final report, but a fake name will be used instead of your real name, so that nobody knows what you have said. Using your answers from the interviews word-for-word will only happen with your permission. The information from this project will be kept on a password-protected device either on the person or in the locked office of Emily Harris. After the project, information will be kept for up to 6 months. After this time, all information will be deleted.

Because you will be asked questions about yourself in the interviews, there is a chance that what you talk about will make you feel sad, embarrassed, or stressed about yourself or other people. If the interviews make you feel upset, Emily, the researcher, will stop the interview and she will try to help you feel better. If you feel sad after the interview, you can call the telephone numbers at the end of this letter to speak with someone who can try and help you to feel better.

## WHAT YOU MAY GAIN

Participating in this study will give you the chance to share your stories, experiences, and ideas of dance and your life. Also, your participation in this research project may help people understand more about dance and people with

different abilities. Lastly, participating in my project may also help create and improve inclusive dance programs and opportunities in the future.

## PARTICIPATION IS YOUR CHOICE

Participation in this study is your choice. During the interviews, you can decide to not answer any questions, take breaks, or end the interview at any time. Lastly, you can stop participating in this project at any time, without anyone being upset with you.

#### THANK YOU

By participating in this project, you will receive a \$25.00 Tim Horton's gift card as a 'thank you' for your help with this project.

#### PUBLICATION OF INFORMATION

This project will be published in a written report as Emily's research project, called a thesis.

## **QUESTIONS OR COMMENTS**

If you have any questions about this project or would like more information, please call or email Emily Harris, the student researcher, or Dr. Colleen Hood, the supervisor. Their phone numbers and email addresses are listed at the beginning of this form.

This study has been approved by a group of people that support research projects. If you have any comments or concerns about the rights of research participants, please call the Research Ethics Office at (905) 688-5550 Extension 3035 or e-mail them at reb@brocku.ca.

If you feel sad and need to speak with someone who can help you right now, you can call someone at the Telephone Crisis Support at Gerstein Crisis Centre. You can call anytime, and it is free. Their phone number is (416) 929-5200. If you want to speak with someone for a long time, you can call the Canadian Mental Health Association to make an appointment with someone who can help you. Their phone number is (416) 789-7957.

IDENTITY IN MOTION 214



## Thank you for your help with this project.

Ι	(Print Name)	agree to participate in this study.
Signature:		
Date:		

#### Appendix G



April 19, 2018

#### GUARDIAN INFORMED CONSENT FORM

**Project Title:** Identities in motion: An exploration of dance and sense of self among individuals with intellectual disabilities

#### **Student Principal Investigator:**

Emily Harris Recreation and Leisure Studies Brock University (647) 278-5078 eh15hq@brocku.ca

#### **Faculty Supervisor:**

Dr. Colleen Hood Recreation and Leisure Studies Brock University (905) 688-5550 Ext. 5120 chood@brocku.ca

#### **INVITATION**

Your child/client is invited to participate in a study that involves research. The purpose of this study is to explore the experiences of dance among individuals with unique challenges. This project seeks to answer the following questions; How do individuals with intellectual disabilities describe their experiences with community-based recreational dance? In what ways, if any, does recreational dance impact individuals with intellectual disabilities as it relates to their sense of self as someone with a disability?

#### WHAT'S INVOLVED

Participation involves participating in two short interviews by the principal researcher, Emily Harris. The interviews will be approximately 30 minutes each and audio-recorded for the researcher's reference during data analysis and creating the final report. The interviews will inquire about participants' experiences with dance and sense of self and will incorporate various ways to facilitate relevant conversation, including artistic expression and referencing photographs and/or videos of the participants' dancing. Provided participant consent, guardians or advocates can be present during the interviews and aid with comprehension and communication, if necessary.

Before the first interview, providing the researcher received consent from those involved, Emily will take photographs and/or videos of each participant during a dance class to help facilitate dialogue during the interviews. All photographs and videos will be given to the participants (both electronically and in physical prints) and deleted after the study is complete. Participants will also be encouraged to bring pictures, videos or memorabilia from any dance experiences to the interviews to help further facilitate conversation. Participants will receive the interview questions in advance, and participants can share as much or as little information as they wish.

Following the interviews, participants will meet with Emily again for about 15 minutes. During this meeting, participants will be showed summaries of the information that was gathered from the interviews. They will be given a chance to clarify this information to help create accurate data. These summaries will be written in simple words and phrases and participants will be able to keep them.

#### POTENTIAL RISKS AND BENEFITS

This study is not intended to cause any harm for participants, however, like participating in any research project, one's anonymity can become compromised, which can result in social risks, such as a loss of privacy or an impacted reputation. To reduce this risk, pseudonyms will be used to reference the participants in the written report as well as the report will not include other identifying information about the participants or *The Dance Ability Movement*. Furthermore, during the documentation of the participants' dancing, the researcher will not concentrate only on the participants to reduce the chances of identifying the participants among the other dancers in the class. She will also rely on the 'zoom' feature on the camera to allow her to document the participants' dancing, while not needing to be close to the participant, which will aid in masking their identity as well. Additionally, the interviews and member checking sessions will be held in a relatively secluded space, yet not completely secluded to protect those involved.

The interviews will explore personal subject matter, which may cause participants to feel negatively about themselves and/or others. Every effort will be made to reduce this risk. During the interviews, Emily will observe the participants for any signs of discomfort. If any signs of distress become apparent, she will stop the interview and support the participant as needed. She will use her education and experience in therapeutic recreation and Nonviolent Crisis Intervention® from Crisis Prevention Institute© to help reduce any negative feelings the participant may experience by offering coping strategies to manage stress and anxiety. Following this, she will consult the participant, along with any accessible guardian/advocate, proving she has the participant's consent, to determine the most appropriate next steps to support the participant's psychological well-being. Emily will then work with the participant and their guardian/advocate to determine if they should end their participation in this study. If participants feel distress following the interviews, the participant or their guardian/advocate can receive support using the information about both immediate and longer-term mental health support provided at the end of the consent forms.

Participation in this study will provide participants with an opportunity to share their experiences and thoughts with others and potentially establish valuable discoveries about themselves and their dance involvement. In addition, participants will also contribute to the growing body of research on integrated dance and intellectual disability, which may ultimately inform future services and opportunities for individuals with disabilities. Last, participants will add to the research that offers the perspectives and voices of people with intellectual disabilities, which may help create more awareness and inclusion among individuals with disabilities.

#### **CONFIDENTIALITY**

The information gathered will be kept confidential, however anonymous quotations may be used in the final report with participant consent. Hard-copy data will be stored in a locked drawer of a locked private office of the principal researcher. Electronic data will be stored on a password protected device and be either kept on the person or locked private office of the researcher. All personal identifiers, including names and contact information will be stored in the same fashion separate from the data collected. Data will be kept for up to 6 months following the completion of participation, after which all hard-copy data will be shredded and disposed in the garbage and all electronic information will be deleted. Access to the information will be restricted to the principal researcher, Emily Harris, the faculty advisor, Dr. Colleen Hood, the two faculty committee members Dr. Maureen Connolly and Dr. Nancy Francis, and a transcriber.

#### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. During the interviews, participants may decline answering any questions, take a break or end the interviews at any point. Additionally, participants can decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which participants are

entitled. Consent will be treated as an ongoing process and any verbal or non-verbal sign that a participant may not be interested in continuing her/his participation will be addressed.

#### **HONOURARIUM**

Participants will receive a \$25.00 Tim Horton's gift card as a token of appreciation for participating in this study.

#### PUBLICATION OF RESULTS

Results of this study will be published as Emily Harris' MA thesis.

## CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact Emily Harris, student principle investigator, or Dr. Colleen Hood, faculty advisor (see above for contact information). This study has been reviewed and received ethics clearance through the Brock University Research Ethics Board (file #17-351). If you have any comments or concerns about research participant rights, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Should a participant require psychological support, participants can call the Telephone Crisis Support at Gerstein Crisis Centre at (416) 929-5200. This free and confidential support line is available 24 hours a day, 7 days a week. For less urgent psychological support, participants can contact Canadian Mental Health Association (CMHA) Toronto at (416) 789-7957 to schedule an appointment with a counsellor.

## Thank you for your assistance with this project.

I(Guardian)	agree to allow	(Participant)
to participate in this research study.		-
Guardian/Advocate Signature:		
Date:		

IDENTITY IN MOTION 218

## **Appendix H**



# We want to hear from you about your experiences with dance!



If you are 18 years of age or older and have unique abilities, you are eligible to participate in a research project that will explore how you feel about dance and yourself.

Participation involves two interactive interviews and related activities. The interviews will be around 30 minutes and will involve a few creative ways to explore your experiences with dance.

If you are interested in learning more about participating in this research project, please call or e-mail Emily Harris, the student researcher, or contact your dance program director.

## Thank you!



## **Emily Harris**

Call: (647) 278-5078 E-mail: eh15hq@brocku.ca

Emily is a graduate student in the department of Applied Health Sciences specializing in Leisure Studies. She is also a dancer just like you!

#### Appendix I



May 28, 2018

Brock University
Department of Recreation and Leisure Studies

St. Catharines, Ontario, Canada L2S 3A1 (905) 688-5550 Ext. 3259

#### **GUARDIAN LETTER OF INVITATION 2**

**Project Title:** Identity in motion: A case study on the dance experiences and sense of self of a dancer with an intellectual disability

Dear Guardian,

As you know, I am currently conducting a research study which explores the experiences of dance among individuals with unique challenges for my Master of Arts degree at Brock University. Originally, I had set out to explore the experiences of dance and sense of self of several individuals with intellectual disabilities. Although I recruited enough participants, I was only able to obtain sufficient data from your son. I attempted to recruit more participants, however unfortunately I was unsuccessful. Therefore, I would like to shift the approach of this research to become a case study around your son and his experiences with dance. This will involve conducting two to three more interviews: one with his dance instructor and the other one or two from people who have close relationships with your son and a good understanding of his relationship with dance. I believe that these interviews, along with the interview that I have already completed with your son, will create a thorough understanding of dance and sense of self in an individual with unique abilities. I am writing to you to inquire about your interest in allowing me to base my research study on your son's experiences with dance and sense of self. In addition, given your significance in your son's life, I am also writing to you to inquire about your willingness to participate in an interview for this revised study.

Participation will involve participating in one interview that I will lead. The interview will be approximately 40 to 50 minutes in length and take place at a time and location based on your convenience. The interview will inquire about your insight and perspective on you son's experiences with dance and his sense of self. After I analyze the data, a summary of the information that I gather will be given to you to check for accuracy and to offer clarification.

Participants will receive a \$25.00 Tim Horton's gift card as an honorarium for participating in this study.

The completion of my degree is not reliant on your participation. Involvement in this study is completely voluntary and will not result in a penalty of any kind.

The findings from this case study may give you a more thorough understanding of your son's participation in his dance classes. Furthermore, participation in this study will contribute to the growing body of research on integrated dance, therapeutic recreation, and intellectual disability. This contribution may ultimately provide new insights, improve the quality of dance and other recreational programs, and increase the amount of such opportunities that are inclusive and accessible for individuals with disabilities.

This study is not intended to cause any harm, however, like all research that involves people, if a participant's identity in this study becomes known to others, there can be social repercussions, such as a loss of privacy or an impacted reputation. To reduce this risk, I will use pseudonyms when referring to participants in the written report as well as refrain from including identifying information about the participants or the individual on whom this case study would be based.

In order for individuals to participate in my study, they will need to sign an informed consent form, which reiterates the associated risk and benefits of participation.

This study has been reviewed and received ethics clearance through the Brock University Research Ethics Board (file #17-351).

If you would like any further information about my research study, please do not hesitate to contact me or my research supervisor (contact information below). If you are willing to offer consent to have this study take place and/or participate in this research project, please refer to the 'Guardian Informed Consent Form 2'.

Thank you for your time and consideration.

Sincerely,

**Emily Harris** 

Ehadis

**Student Principal Investigator:** 

Emily Harris Recreation and Leisure Studies Brock University (647) 278-5078 eh15hq@brocku.ca **Faculty Supervisor:** 

Dr. Colleen Hood Recreation and Leisure Studies Brock University (905) 688-5550 Ext. 5120 chood@brocku.ca

#### Appendix J



May 28, 2018

#### GUARDIAN INFORMED CONSENT FORM 2

**Project Title:** Identity in motion: A case study on the dance experiences and sense of self of a dancer with an intellectual disability

#### **Student Principal Investigator:**

Emily Harris Recreation and Leisure Studies Brock University (647) 278-5078 eh15hq@brocku.ca

#### **Faculty Supervisor:**

Dr. Colleen Hood Recreation and Leisure Studies Brock University (905) 688-5550 Ext. 5120 chood@brocku.ca

#### **INVITATION**

You are invited to participate in a study that involves research. The purpose of this study is to explore the experiences of dance among individuals with unique challenges. This project seeks to answer the following questions; How might an individual with an intellectual disability describe his experience with community-based recreational dance? In what ways, if any, does recreational dance impact an individual with an intellectual disability as it relates to his sense of self?

#### WHAT'S INVOLVED

This study will explore dance and sense of self through a case study of the experiences and perspectives of one individual with unique abilities and challenges who is involved with dance. This will involve conducting two to three more interviews: one with his dance instructor and the other one or two from people who have close relationships with your son and a good understanding of his relationship with dance.

Participation involves participating in one interview by the principal researcher, Emily Harris. The interview will be approximately 40 to 50 minutes and audio-recorded for the researcher's reference during data analysis and creating the final report. The interview will inquire about your insight and perspective on your child's experiences with dance and sense of self. You are able to view the interview questions in advance and can share as much or as little information as you wish.

Once the information from the interview has been analyzed, Emily will speak with participants again for about 15 minutes. During this time, participants will be given a summary of the information that was gathered and interpreted from the interviews. This is an opportunity to clarify this information to help create accurate data.

#### POTENTIAL RISKS AND BENEFITS

This study is not intended to cause any harm for participants, however, like participating in any research project, one's anonymity can become compromised, which can result in social risks, such as a loss of privacy or an impacted reputation. To reduce this risk, pseudonyms will be used to reference each participant in the written report. The report will also exclude other identifying information about the participants or the individual on whom this case study would be based. Additionally, the interviews will be held in a relatively secluded space, yet not completely secluded to protect those involved. Another social risk to the individual on whom this case study will be based, is that this individual may be exposed to or learn about negative perceptions of the other informants regarding the individual of study, which may negatively impact the relationship between this individual and the other participants. To mitigate this risk, contact information for mental health support services are provided (at the end of this form). Such services can counsel participants through relationship challenges to help re-establish their relationships. Similarly, the interviews will explore personal subject matter, which may cause participants (both informant and individual on whom this case study will be based) to experience negative emotions. Every effort will be made to reduce this risk. During the interview, if any signs of distress become apparent, Emily will stop the interview and support the participant as needed. If any participant feels distress following the interviews, contact information for both immediate and longer-term mental health support is provided at the end of this consent form.

Participation in this study will provide each involved participant with an opportunity to share their experiences and thoughts with others and potentially establish valuable discoveries about themselves. In addition, participants will also contribute to the growing body of research on integrated dance and intellectual disability, which may ultimately inform future services and opportunities for individuals with disabilities.

#### **CONFIDENTIALITY**

The information gathered will be kept confidential, however anonymous quotations may be used in the final report with participant consent. Hard-copy data will be stored in a locked drawer of a locked private office of the principal researcher. Electronic data will be stored on a password protected device and be either kept on the person or locked private office of the researcher. All personal identifiers, including names and contact information will be stored in the same fashion separate from the data collected. Data will be kept for up to 6 months following the completion of participation, after which all hard-copy data will be shredded and disposed in the garbage and all electronic information will be deleted. Access to the information will be restricted to the principal researcher, Emily Harris, the faculty advisor, Dr. Colleen Hood, two faculty committee members Dr. Maureen Connolly and Dr. Nancy Francis, and a transcriber.

#### **VOLUNTARY PARTICIPATION**

Participation in this study is completely voluntary. During the interviews, participants may decline answering any questions, take a break or end the interviews at any point. Additionally, participants can decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which participants are entitled. My completion of my degree is not reliant on your participation.

#### **HONOURARIUM**

Participants will receive a \$25.00 Tim Horton's gift card as a token of appreciation for participating in this study.

#### PUBLICATION OF RESULTS

Results of this study will be published as Emily Harris' MA thesis and may also be published in peer-reviewed journals and conference proceedings. Results may also be presented in conferences.

#### CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact Emily Harris, student principle investigator, or Dr. Colleen Hood, faculty advisor (see above for contact information). This study has been reviewed and received ethics clearance through the Brock University Research Ethics Board (file #17-351). If you have any comments or concerns about research participant rights, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca

Should you or your child require psychological support, call the Telephone Crisis Support at Gerstein Crisis Centre at (416) 929-5200. This free and confidential support line is available 24 hours a day, 7 days a week. For less urgent psychological support, contact Canadian Mental Health Association (CMHA) Toronto at (416) 789-7957 to schedule an appointment with a counsellor.

#### Thank you for supporting this project.

Ι	consent to have this research project be based on my child.
Guardian Signature:	
Date:	
I	consent to participating in this research study.
Participant Signature:	
Date:	

## Appendix K

May 10, 2018

#### SCRIPT TO DANCER PARTICIPANT

#### Hi Miller!

You gave me a lot of helpful information about yourself and dance. I was going to make a project where I would ask a few different people about their feelings towards dance. Instead of doing this, I would like to make my project all about you and your experiences with dance. To do this, I would talk to two people who are important to you and who know about your relationship with dance very well, perhaps your mother and your dance instructor. I would ask them how they feel about you and your experiences with dance. At any time, you can tell me or your mom that you do not want to continue being part of this project, and I will end this project.

After I speak with them, I will meet with you and tell you what they said to make sure that you feel that what they said was right. After that, I will put the things you told me and things that they told me together to help me understand how you experience dance and what dance does for you. In the end, I will write a written report.

#### **Risks:**

There is a chance that people will find out that this study will be about you. To try to stop this risk, I will use pretend names for you and the other two people teaching me about you. Another risk is that you may not like what the people I speak with will say about you and/or your experiences with dance. This may cause you to feel upset or embarrassed. To help you if this does happen, I will give your mother information of people who you may be able to help you with your feelings.

#### **Benefits:**

Having this project be all about you and your experiences with dance may help you understand how two people close to you feel about you and your relationship with dance. This might make you feel happy and proud of yourself and happy with your relationship with these people. Also, listening to what these two people think of you might help you learn more about yourself and/or give you new ideas about you and dance. Lastly, this project will teach others about dance and people with disabilities.

Is this project something that you would be interested in?

#### Appendix L



June 5, 2018

Brock University
Department of Recreation and Leisure Studies

St. Catharines, Ontario, Canada L2S 3A1 (905) 688-5550 Ext. 3259

#### LETTER OF INVITATION

**Project Title:** Identity in motion: A case study on the dance experiences and sense of self of a dancer with an intellectual disability

Dear Potential Participant,

I am a graduate student in the department of Applied Health Sciences, specializing in Recreation and Leisure Studies, at Brock University. For my Master of Arts degree, I am currently conducting a research study which will explore the experiences of dance among individuals with unique challenges. The study is entitled "Exploring dance and sense of self: A phenomenological case study of a dancer with an intellectual disability". This research study is under the supervision of Dr. Colleen Hood, a professor at Brock University. Originally, I had set out to explore the experiences of dance and sense of self of several individuals with intellectual disabilities. Although I recruited enough participants, I was only able to obtain sufficient data from one participant. Based on these results, I am shifting the approach to this research to become a case study around one individual. Given your significant relationship with this individual, I am writing to you to inquire about your willingness to participate in this study.

Past research shows that dance, along with other leisure pursuits, can provide many benefits to quality of life and help people live well. This study will aim to understand the experiences of individuals with unique abilities with recreational dance. Further, I hope to explore the ways, if any, that dance impacts the sense of self among people with different abilities and challenges.

Participation in this study will involve participating in one interview that I will lead. The interview will be approximately 30 to 40 minutes in length and take place at a time and location based on your convenience. The interviews will inquire about your insight and perspectives on this dancer's experiences with dance and their sense of self. After I analyze the data, a summary of the information that I gather will be given to you to check for accuracy and to offer clarification.

Participants will receive a \$25.00 Tim Horton's gift card as an honorarium for participating in this study.

The completion of my degree is not reliant on your participation. Involvement in this study is completely voluntary and will not result in a penalty of any kind.

Participation in this study will contribute to the growing body of research on integrated dance, therapeutic recreation, and intellectual disability. This contribution may ultimately provide new insights, improve the quality of dance and other recreational programs, and increase the amount of such opportunities that are inclusive and accessible for individuals with disabilities.

This study is not intended to cause any harm, however, like all research that involves people, if a participant's identity in this study becomes known to others, there can be social repercussions, such as a loss of privacy or an impacted reputation. To reduce this risk, I will use pseudonyms when referring to participants in the written report as well as refrain from including identifying information about the participants or the individual on whom this case study would be based.

In order for individuals to participate in my study, they will need to sign an informed consent form, which reiterates the associated risk and benefits.

This study has been reviewed and received ethics clearance through the Brock University Research Ethics Board (file #17-351).

If you would like any further information about my research study, please do not hesitate to contact me or my research supervisor (contact information below). If you are willing to participate in this research study, please refer to the 'Dance Instructor Informed Consent Form'.

Thank you for your time and consideration.

Sincerely,

**Emily Harris** 

Ehadis

**Student Principal Investigator:** 

Emily Harris Recreation and Leisure Studies Brock University (647) 278-5078 eh15hq@brocku.ca **Faculty Supervisor:** 

Dr. Colleen Hood Recreation and Leisure Studies Brock University (905) 688-5550 Ext. 5120 chood@brocku.ca

#### Appendix M



June 5, 2018

#### INFORMED CONSENT FORM

**Project Title:** Identity in motion: A case study on the dance experiences and sense of self of a dancer with an intellectual disability

#### **Student Principal Investigator:**

Emily Harris Recreation and Leisure Studies Brock University (647) 278-5078 eh15hq@brocku.ca

#### **Faculty Supervisor:**

Dr. Colleen Hood Recreation and Leisure Studies Brock University (905) 688-5550 Ext. 5120 chood@brocku.ca

#### **INVITATION**

You are invited to participate in a study that involves research. The purpose of this research is to explore the experiences of dance among individuals with unique challenges. This study seeks to answer the following questions; How might an individual with an intellectual disability describe his experience with community-based recreational dance? In what ways, if any, does recreational dance impact an individual with an intellectual disability as it relates to his sense of self?

#### WHAT'S INVOLVED

Participation involves participating in one interview by the principal researcher, Emily Harris. The interviews will be approximately 30 to 40 minutes and audio-recorded for the researcher's reference during data analysis and creating the final report. The interviews will inquire about your insight and perspective on one of your dance student's experiences with dance and sense of self. You will be able to view the interview questions in advance and can share as much or as little information as you wish. After the data has been analyzed, Emily will speak with participants again for about 15 minutes. During this time, you will be given a summary of the information that was gathered and interpreted from the interviews. This is an opportunity to clarify this information to help create accurate data.

#### POTENTIAL RISKS AND BENEFITS

This study is not intended to cause any harm for participants, however, like participating in any research, one's anonymity can become compromised, which can result in social risks, such as a loss of privacy or an impacted reputation. To reduce this risk, pseudonyms will be used to reference the participants in the written report as well as the report will not include other identifying information about the participants or the individual on whom this case study would be based. Additionally, the interviews will be held in a relatively secluded space, yet not completely secluded to protect those involved.

Participation in this study will provide participants with an opportunity to share their experiences and thoughts with others and potentially establish valuable discoveries about themselves. In addition, participants will also contribute to the growing body of research on integrated dance and intellectual disability, which may ultimately inform future services and opportunities for individuals with disabilities.

#### **CONFIDENTIALITY**

The information gathered will be kept confidential, however anonymous quotations may be used in the final report with participant consent. Hard-copy data will be stored in a locked drawer of a locked private office of the principal researcher. Electronic data will be stored on a password protected device and be either kept on the person or locked private office of the researcher. All personal identifiers, including names and contact information will be stored in the same fashion separate from the data collected. Data will be kept for up to 6 months following the completion of participation, after which all hard-copy data will be shredded and disposed in the garbage and all electronic information will be deleted. Access to the information will be restricted to the principal researcher, Emily Harris, the faculty advisor, Dr. Colleen Hood, two faculty committee members Dr. Maureen Connolly and Dr. Nancy Francis, and a transcriber.

#### **VOLUNTARY PARTICIPATION**

Participation in this study is completely voluntary. During the interviews, participants may decline answering any questions, take a break or end the interviews at any point. Additionally, participants can decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which participants are entitled. The completion of my degree is not reliant on your participation.

#### **HONOURARIUM**

Participants will receive a \$25.00 Tim Horton's gift card as a token of appreciation for participating in this study.

#### **PUBLICATION OF RESULTS**

Results of this study will be published as Emily Harris' MA thesis and may also be published in peer-reviewed journals and conference proceedings. Results may also be presented in conferences.

#### CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact Emily Harris, student principle investigator, or Dr. Colleen Hood, faculty advisor (see above for contact information). This study has been reviewed and received ethics clearance through the Brock University Research Ethics Board (file #17-351). If you have any comments or concerns about research participant rights, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Ι	consent to participating in this research study.	
Participant Signature:	Date:	

Thank you for your assistance with this research!

#### Appendix N

#### **INTERVIEW GUIDES**

**Project Title:** Identity in motion: A case study on the dance experiences and sense of self of a dancer with an intellectual disability

#### **DANCER INTERVIEW GUIDE**

#### Dance:

- 1. What are your favorite things about dance class? Your least favorite thing? (If examples are needed, is it the music, the people, how dance makes you feel, related to being in a group, the physical aspects of dance etc.)
- 2. Which photograph do you like the best? The least? Why?
- 3. When you are dancing, what feelings do you have? (Present a few photographs/videos, and ask how he/she feels in each?)
  - a. How do you feel when you wake up on a day that you have dance class?
  - b. How do you feel when you are walking into the dance studio?
  - c. How do you feel when the class is over?
  - d. How would you feel if you were not able to dance anymore?
- 4. What are your feelings about the other dancers in your class? How do you think they feel about you?
- 5. If dancing was a color, what color would it be and why?
- 6. How would you title each picture?
- 7. How do you feel when you look at the photographs/videos?
- 8. If you could choose any activity to do, would you choose dancing? Why or why not?
- 9. Create a picture of you dancing.
  - a. Describe this picture. How are you feeling in this picture? What are you thinking about?

#### **Sense of Self:**

- 1. How would you describe yourself? (show a photograph and/or create a picture) (physical characteristics, personality, strength/talents/abilities, interests, hobbies, challenges, social connections)
  - a. Who are you on the outside? Who are you on the inside?
  - b. What do you like the most about yourself?
  - c. What do you like the least about yourself?
  - d. What might you like to change if you could?
  - e. What do you wish more people knew about you?
- 2. How would your friends and family describe you?
  - a. How would your family describe you?

- b. How would your friends describe you?
- 3. How would you describe yourself as a friend? As a son/daughter? As a sibling?
- 4. Which photograph taken from dance class shows you at your best? What does this photograph show about you?

## **Dance and Sense of Self:**

- 1. What parts of you do you get to use or show when you are dancing? Is there a photograph that shows that part of you?
- 2. What feelings do you have when you are dancing?
- 3. What about dance do you enjoy the most? The least?
- 4. What are the best things about dance for you?
- 5. How important is dance to you in terms of how you feel about yourself?

#### **GUARDIAN INTERVIEW GUIDE**

#### Sense of Self:

- 1. How would you describe Miller? (personality, strength/talents/abilities, interests, challenges, etc.)
  - a) What are you most proud of Miller for?
- 2. How do you think Miller thinks of himself?
  - a) What might he like to change if he could?

#### Dance:

- 1. In the interview with Miller, he talked about the dance activities that he is involved with:
  - a) Integrated dance classes
  - b) Community dance socials

Are there any other dance activities that he regularly participates in?

- 2. What are the benefits of dance for Miller?
- 3. Miller stated that to him, dance is good because it makes him happy. In your words and from your own perspective, how do you think Miller feels about dance?
- 4. Miller stated that dance activities makes him happy because he gets to have fun with his friends. With this in mind, how would you describe his relationship with his dance friends? How is this relationship similar or different from his relationship with other friends and family? In what ways do these dance relationships benefit or challenge Miller?
- 5. Miller described dance classes as a chance to learn new things. In your opinion, what is it about dance classes that allow him to learn new things? What kinds of things has Miller learned as a result of participating in dance?
- 6. B explained that dance allows him to be kind by helping new dancers and assisting with things like helping to move the ballet barres. With this in mind, how do you think dance allows Miller to develop and express his kindness and helpfulness towards others? In what ways do his experiences of being helpful others through dance translate to other parts of his life, if at all?
- 7. From your perspective, how do you think Miller generally feels when he is dancing? How does he show these feelings?
- 8. Miller stated that his dance friends are excited to see him and think that he's funny. From your perspective, how would the other dance friends describe Miller? In what ways is this description similar or different from the way others would describe Miller?
- 9. From your perspective, what does dance mean to Miller?
- 10. How important is dance for Miller?
- 11. The research on integrated dance addresses a lack of dance opportunities that are accessible and inclusive for people with disabilities. Do you think there is anything Miller would change about his opportunities to experience dance in the way that he might like?

12. While there are some dance opportunities that genuinely integrate people with all different abilities, many dance opportunities that people with disabilities are involved with, are to some extent segregated as they specifically target individuals with disabilities. Do you think Miller experiences any limitations regarding dance experiences?

#### **Dance and Sense of Self:**

- 1. How does dance allow Miller to develop or express the way he sees himself?
  - a) His/her generosity/kindness
  - b) His/her sense of humor
  - c) His/her value of being physically fit and active
  - d) His identity of being a good friend
- 2. How important is dance to Miller in terms of how he feels about himself?
- 3. In what ways, if any, has dance impacted the way Miller sees himself as someone with an intellectual disability?

#### COMMUNITY MEMEBER INTERVIEW GUIDE

#### **Sense of Self:**

- 1. How would you describe Miller? (personality, strengths/talents/abilities, and/or challenges)
- 2. How do you think Miller thinks of himself?

#### Dance:

- 1. How do you know Miller? How would you describe your relationship with Miller?
- 2. What are the community dances like? How is Miller involved with them? What role does he have?
- 3. Miller said that dance is good because it makes him happy. In your own words and from you own perspective, how do you think Miller feels about dance? What parts of the community dances connect to these feelings?
- 4. Miller stated that dance class makes him happy because he gets to have fun with his friends. With this in mind, what kind of relationship does he have with his peers in the dances?
- 5. Miller described dance class as a chance to learn new things. How would you say the community dances allow him to learn new things?
- 6. Miller stated that dance allows him to be kind to others by helping others. With this in mind, how do you think the dances allows Miller to develop and express his kindness and eagerness to help others?
- 7. How do you think Miller generally feels when he is dancing?
- 8. Miller stated that his dance friends are excited to see him and think that he's a funny guy. From your perspective, how would the other dancers in the community dances describe Miller?

#### **Dance and Sense of Self:**

- 1. Miller described various aspects of himself:
  - e) His/her helpfulness/kindness
  - f) His/her sense of humor
  - g) His/her value of being physically fit and active
  - h) His identity of being a good friend
  - i) People like to be around him

How would you say that dance allows Miller to develop or express these aspects of himself?

2. How important would you say dance is to Miller in terms of developing a positive sense of self?

#### DANCE INSTRUCTOR INTERVIEW GUIDE

#### **Sense of Self:**

- 1. How would you describe Miller? (personality, strengths/talents/abilities, and/or challenges)
- 2. How do you think Miller thinks of himself?

#### Dance:

- 1. How would you describe your relationship with Miller?
- 2. What are the integrated dance classes like? How does Miller participate in them?
- 3. Miller said that dance is good because it makes him happy. In your own words and from you own perspective, how do you think Miller feels about dance? What parts of the dance classes connect to these feelings?
- 4. Miller stated that dance class makes him happy because he gets to have fun with his friends. With this in mind, what kind of relationship does he have with his peers in the dance classes?
- 5. Miller described dance class as a chance to learn new things. How would you say the dance classes allow him to learn new things?
- 6. Miller stated that dance allows him to be kind to others by helping others. With this in mind, how do you think the dance classes allow Miller to develop and express his kindness and eagerness to help others?
- 7. How do you think Miller generally feels when he is dancing?
- 8. Miller stated that his dance friends are excited to see him and think that he's a funny guy. From your perspective, how would the other dancers in the classes describe Miller?

#### **Dance and Sense of Self:**

- 1. Miller described various aspects of himself:
  - i) His/her helpfulness/kindness
  - k) His/her sense of humor
  - 1) His/her value of being physically fit and active
  - m) His identity of being a good friend
  - n) People like to be around him

How would you say that dance allows Miller to develop or express these aspects of himself?

2. How important would you say dance is to Miller in terms of developing a positive sense of self?

## Appendix O DATA CODING EXAMPLE

## **Legend of Colours**

#### **Potential Themes:**

Personal Information

**Dance Information** 

Personal Growth

Connection

**Character Strengths** 

Stigmatization/Normalization

## **General Codes:**

Sense of Self

Overall Relationship with Dance

Specific Experiences with Dance

Random/Less Relevant Information

**Background Information on Dance** 

## **Transcription Results**

S1 00:01	So that's okay, they seem to be going.
S2 00:07	Okay.
S1 00:07	Fingers crossed [laughter]. Okay. So how would you, in your own words, describe Brandon? So you can think about his strengths, his personalities, his challenges, his talents?
S2 00:23	He's a really friendly, energetic, outgoing young guy. Very, very personable. Loves to just get right in there and ask you a question. He's very, I guess, forthright; he's no qualms about like, "Hey, can I ask you this?" or, "Hey" he's not shy at all.
S1 00:48	Totally. Just goes for it?
S2 00:49	Just goes for it. Very outgoing, personable guy.
S1 00:53	Totally. That's totally how I felt, too, when I met him. Even, right away, I came in
S2 00:58	Right, "Hey!"
S1 00:59	Yeah. First person I met

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S2 01:01	Yeah, no qualms, he'll go right over to you and be like, "Hey, who are you? Why are you here? Nice to meet you," that sort of thing.
S1 01:07	Amazing. That's cool. So I asked Brandon a few things about how he feels about himself. <b>How would you say Brandon sees himself?</b> Looking at him, I guess, like you said, over the years and in class, how would you think that he sees himself in terms of his self-esteem or his sense of self, basically?
S2 01:40	I'd like to think he's got a really positive sense of self because he gives the perception that he's always happy and ready to go and whatnot. So I hope that he feels that way-
S1 01:57	He definitely does. Yeah, just the yeah.
S2 01:59	Okay, good. That's wonderful because that's kind of the persona that he gives off and if you can internalize that's a great bout of confidence to have. In the classroom, he's definitely very confident.
S1 02:15	[inaudible] that comes across, yeah.
S2 02:17	Oh, yeah. When you're doing moves and whatnot, I'll be like, "Well, okay, we got it, but let's try to fix this." "No, I got it. I totally got this." And I'm like, "So close. Can we change this little thing?" "Nope, I got it." "Okay [laughter], you know what? That's all right."
S1 02:33	Yeah. Nice. Okay, cool. I'm going to make sure this is still yeah, okay. We're good. So just to clarify, Robin mentioned that he's involved with two classes, currently. It was the tap and the
S2 02:50	And sort of the hip-hop.
S1 02:52	Yeah? Okay. So it's those two and they're both the Friday?
S2 02:57	Yes, both Friday nights.
S1 02:58	Okay. So in my interview with Brandon, he said that dance is good because it makes him happy. And in your own words and from your own perspective, how do you think he feels about dance?
S2 03:15	I think he really enjoys it. I think he really enjoys, not only being able to express himself and show off, he always says his "cool moves" and whatnot, but the sense of community. I don't know if you saw him interact with some of the younger dancers in the tap class, because it is a mixed ages class, he's really exceptional with taking on a leadership role and guiding some of the younger boys, which is just awesome. So I hope he sees that as part of dance because he just so naturally takes to the different roles in the different classes. Whereas the hip-hop is more of his peers, the tap is more of like, "Okay, buddy, let's help you across the floor and we'll do this together."
S1 04:02	So he's helping the other dancers?
S2 04:05	He is. Yeah, yeah. He's helping the younger ones.