

SELF-CONCEPT AND EMOTIONAL WELL-BEING IN INDIVIDUALS WITH  
DEVELOPMENTAL DISABILITIES INVOLVED IN SPECIAL OLYMPICS

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## Abstract

Individuals with developmental disabilities (DD) are known to have lower levels of physical and social self-concept and emotional well-being compared to typically developing individuals. Little is known about the individual and family predictors of these constructs, and researchers have typically relied on proxy measures rather than self-report. In a sample of 51 caregivers and 51 athletes with DD involved in Special Olympics (SO), we examined the individual predictors (e.g., age, sex, BMI, emotional and behavioural problems, and SO participation) and family predictors (e.g., caregiver mental health, family functioning, and expressed emotion) of self-reported physical and social self-concept (Study One) and emotional well-being (Study Two). Age, total difficulties, and SO participation were significantly related to social self-concept, whereas age and BMI were significantly related to physical self-concept. None of the family factors were related to either social or physical self-concept. Both individual factors and family factors (i.e., BMI, emotional and behavioural problems, prosocial behaviour, expressed emotion, and family functioning) were significantly related to indicators of emotional well-being. The results have important implications for understanding and promoting social and physical self-concept and emotional well-being in individuals with DD.

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## General Introduction

With over 4.4 million registrants in over 170 countries around the world, Special Olympics (SO) is the largest sport organization for people with developmental disabilities (DD), a term that includes individuals with intellectual disability (ID) and autism spectrum disorder (ASD; Special Olympics, 2015a). Intellectual disability is characterized by deficits in intellectual and adaptive functioning, originating during the developmental period, and ASD is defined by persistent deficits in social communication and social interaction and restricted, repetitive patterns of behaviour, interests or activities present during the early developmental period (American Psychiatric Association (APA), 2013). Both are considered neurodevelopmental disorders (APA, 2013). In Canada alone, SO serves approximately 35,000 individuals with DD with a membership of varying ages, abilities, and socio-economic backgrounds (Special Olympics, 2015b). The aim of SO is to provide opportunities for individuals with DD to develop physical fitness, foster relationships, and improve well-being through sport. SO provides an ideal sample of individuals with DD because programs do not exclude based on ability levels, age, or financial need. While not necessarily representative of all individuals with DD, sampling at community-based levels has been employed to understand the psycho-social and health outcomes for individuals with DD more broadly (e.g., Adler, Duigan, & Woodhouse, 2004; Harris, Rosenberg, Jangda, O'Brien, & Gallagher, 2003; Turner, Sweeney, Kennedy, & Macpherson, 2008; Weiss & Riosa, 2015).

Participation in SO has been associated with a number of positive outcomes including improved self-concept (Gibbons & Bushakra, 1989; Weiss, Diamond, Demark,

& Lovald, 2003) and emotional well-being (Glidden, Bamberger, Draheim, & Kersh, 2011). Global self-concept is defined as a person's perceptions of his or her own general abilities, characteristics, and competencies (Shavelson, Hubner, & Stanton, 1976). Two important domains of global self-concept are 1) physical self-concept, which, when positive, refers to general feelings of happiness, contentment, and pride in one's appearance and physical competence (Fox & Corbin, 1989), and 2) social self-concept, which refers to self-perceptions of social acceptance (Bracken, 1996). A positive global self-concept is critical for positive development (Maïano, Bégarie, Morin, & Ninot, 2009; Sonstroem, 1997; Wylie, 1989), and is associated with fewer mental health issues (Dagnan & Sandhu, 1999; Silon & Harter, 1985). Individuals with DD have been shown to have lower levels of global self-concept (Evans, 1998; Levy-Schiff, Kedem, & Sevilla, 1990), social self-concept (Bauminger & Kasari, 2000), and physical concept (Bauminger, Shulman, & Agam, 2004) compared to their typically developing peers. Emotional well-being is a subjective and global judgment of life experiences, and reflects an appraisal of life satisfaction, positive affect, and the absence of negative affect (Emerson & Hatton, 2008). Emotional well-being is another area of particular concern when considering the quality of life of individuals with DD, as research indicates that this group experiences lower levels compared to typically developing individuals throughout the lifespan (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008).

Bronfenbrenner (1977) argues for research that examines the full ecology of human development, taking into account individuals and the families in which they are embedded. There is a paucity of research examining the individual predictors (e.g., age, sex, intellectual functioning, BMI, emotional and behavioural problems, and SO

participation) and family predictors (e.g., caregiver mental health, family functioning, expressed emotion, and socio-economic status) of self-concept and emotional well-being for individuals with DD involved with SO, and to date no study has examined these individual and family predictors in combination. As well, research in the area of self-concept and emotional well-being typically relies on proxy reporting, which has questionable reliability and validity when measuring the internal states of individuals with DD (Perry & Felce, 2002; McGillivray, Lau, Cummins, & Davey, 2009; Perkins, 2007), and researchers strongly recommend the use of self-report when assessing internal states (e.g., Cummins, 2002).

In the first study, we examined the individual predictors (e.g., age, sex, BMI, emotional and behavioural problems, and SO participation) and family predictors (e.g., caregiver mental health, family functioning, and expressed emotion) of physical and social self-concept in adolescents and young adults involved with SO. For the second study, we explored the same individual and family predictors of emotional well-being in these athletes. In the second study we also investigated intellectual functioning as an individual level predictor and socio-economic status as a family level predictor of emotional well-being, based on previous research that has examined socio-economic status (Emerson & Hatton, 2008) and level of functioning (Witwer & Lecavalier, 2008) as potential indicators of emotional well-being. By exploring correlates of self-concept and emotional well-being, these studies provide a critical foundation for identifying intervention targets that promote quality of life. While highlighting current gaps in the literature, the findings offer direction to future research into measuring the self-concept and emotional well-being of individuals with DD.

Study 1: The predictors of physical and social self-concept for adolescents and young adults with DD involved in Special Olympics

Self-concept is defined as a person's perceptions of his or her own abilities, characteristics, and competencies (Shavelson et al., 1976). The theoretical model of self-concept is multidimensional and hierarchically organized with global self-concept at the top of the model, which is further divided into domains and subdomains (See Figure 1; Fortes, Ninot, & Delignières). An important domain of self-concept is physical self-concept, which, when positive, refers to general feelings of happiness, contentment, and pride in one's appearance and physical competence (Fox & Corbin, 1989). According to Fox and Corbin (1989), physical self-concept can be broken down into four more specific subdomains: physical condition (perceptions of one's level of physical fitness and stamina), sport competence (perceptions of sport and athletic ability), physical strength (perceptions of strength and muscle development) and attractive body (perceived attractiveness of the body and confidence in one's appearance); (See Figure 1). Another important domain of global self-concept is social self-concept, which refers to self-perceptions of social acceptance (Bracken, 1996). In other words, a positive social self-concept involves the perceived ability to form and maintain friendships and other positive relationships.

The attainment of a positive global self-concept is a fundamental, developmental need for individuals with and without developmental disabilities, a term that includes individuals with intellectual disability (ID) and autism spectrum disorder (ASD); (Baumeister & Leary, 1995; Bauminger & Kasari, 2000; Ladd, 1999). A positive global self-concept is important for healthy adjustment (Sonstroem, 1997), independence

(Wylie, 1989), and inclusion (Mañano, Bégarie, Morin, & Ninot, 2009; Mañano, Ninot, Bruant, & Benattar, 2003; Ninot, Bilard, Delignieres, & Sokolowski, 2000). Individuals with DD who have poor global self-concept are vulnerable to mental health issues, including anger, depression (Dagnan & Sandhu, 1999), and anxiety (Silon & Harter, 1985), and individuals with DD have been shown to have lower levels of global self-concept compared to their typically developing peers (Evans, 1998; Levy-Schiff et al., 1990) and compared to individuals with emotional difficulties or learning disorders (Jones, 1985).

A considerable amount of research indicates that individuals with DD may have lower levels of social self-concept, more specifically. Throughout the lifespan, individuals with DD experience lower levels of social acceptance compared to their peers (Bauminger, Shulman, & Agam, 2004; Gilmore & Cuskelly, 2014; Leffert, Siperstein, & Millikan, 2000; Stancliffe et al., 2010). Children and adolescents with DD have difficulty forming and maintaining friendships (Guralnick, 1990), spend more time in solitary play (Buttimer & Tierney, 2005), and interact less often with peers than their typically developing classmates (Bauminger et al., 2004; Bronson, Hauser-Cram, & Warfield, 1995; Solish, Perry, & Minnes, 2010). Children with ASD, in particular, experience loneliness more intensely and more frequently compared to typically developing individuals (Bauminger & Kasari, 2000; Bauminger et al., 2003). In a study examining self-reported social acceptance in 16 children and adolescents with high-functioning ASD (8-17 years old), levels of social acceptance were significantly lower for the individuals with ASD compared to their typically developing peers (Bauminger et al., 2004). Similarly, children with ASD have been found to report lower levels of social

competence compared to their typically developing peers (Capps, Sigman, & Yirmiya, 1995). Individuals with ID (without ASD) also experience difficulties with social acceptance. They are less socially engaged (Emerson & McVilly, 2004; Lippold & Burns, 2009), their friendships primarily consist of paid staff, family, and others with ID (Bigby & Knox, 2009), and they report significantly lower levels of popularity compared to their typically developing peers (Jones, 1985).

In contrast, very little research has investigated the physical self-concept of individuals with DD compared to their peers. One study found no significant differences between the physical self-concept of children who were identified as “educable mentally retarded” compared to typically developing children and those with other disabilities (Jones, 1985); however, it is unclear whether these children met diagnostic criteria for ID or ASD. Bauminger et al. (2004) found that children with ASD rated their physical competence significantly lower than the typically developing comparison group. These equivocal findings highlight the need for research on the physical self-concept of individuals with DD. The objective of the current study is to examine the individual predictors (e.g., age, sex, BMI, emotional and behavioural problems, and SO participation) and family predictors (e.g., caregiver mental health, family functioning, and expressed emotion) of physical and social self-concept for adolescents and young adults with DD involved in SO.

A strong conceptual and theoretical rationale exists for examining individual and family factors in the study of self-concept. Bronfenbrenner’s (1977) ecological model of human development highlights the importance of examining individuals within the context of their family and community. This approach to research provides a more

comprehensive picture of human development compared to simply examining any one factor on its own. Researchers in the area of self-concept have set a precedent for considering characteristics of the individual as well as the environmental influences of family (Birndorf, Ryan, Auinger, & Aten, 2005). These factors provide a robust framework for researchers and practitioners who aim to understand and improve the self-concept of individuals with DD.

### **Individual Factors**

Sex, age, and Body Mass Index (BMI), defined as a weight-to-height ratio used as an indicator of unhealthy and healthy weight, are likely important individual predictors of physical and social self-concept (Marsh, 1989). For instance, typically developing males tend to have higher ratings of physical self-concept than females (Maïano, Ninot, & Bi-lard, 2004). In a sample of typically developing elementary and secondary students (584 girls, 514 boys), Klomsten, Skaalvik, and Espnes, (2004) found that that boys had more positive ratings than girls across eight physical subdomains (e.g., appearance, body fat, sports competence, physical activity, endurance, strength, coordination, and health) and had higher overall physical self-concept. For social self-concept, some studies show no sex differences (e.g., Crain & Bracken, 1994), while others indicate that females have better social self-concepts than boys (e.g., Osborne & LeGette, 1982). Age is also related to physical and social self-concept for typically developing individuals (Marsh, 1989), with a decline in self-concept during early and middle adolescence (Klomsten et al., 2004; Marsh, 1989; Wigfield & Eccles, 1994) and then an increase in self-concept during late adolescence and early adulthood (Marsh, 1989). BMI is another individual level variable associated with physical and social self-concept among typically developing

individuals (e.g., McCabe & Ricciardelli, 2003, 2005; Ricciardelli, McCabe, Holt, & Finemore, 2003; Stice, 2002). Petrie, Greenleaf, and Martin (2010) measured the physical self-concept and body satisfaction of typically developing students in grades six through eight (629 boys and 659 girls), showing that BMI was a significant predictor of body satisfaction, with low BMI correlated with greater body satisfaction for both boys and girls. Similarly, O'Dea (2006) found a connection between high BMI and low social self-concept in a study of 80 typically developing girls. Research has yet to examine whether sex, age, or BMI are related to physical and social self-concept in youth with DD.

There is an important connection between self-concept and emotional and behavioural problems, particularly with regard to social self-concept (e.g., Howell et al., 2007); however, only one study has examined the association between physical self-concept and emotional and behavioural problems in typically developing adolescents, suggesting that those with a broad array of clinical diagnoses have poorer physical self-concepts than non-clinical peers (Simons, Capiro, Adriaenssens, Delbroek, & Vandebussche, 2012). For social self-concept among typically developing youth, externalizing behaviour is often associated with peer rejection and loneliness (Ladd & Troop-Gordon, 2003; Pederson, Vitaro, Barker, & Borge, 2007; Scholtens, Diamantopoulou, Tillman, & Rydell, 2012). In a longitudinal study of individuals with ID, Howell, Hauser-Cram, and Kersh (2007) measured the externalizing behaviour of 82 children with ID at age three and measured their feelings of loneliness at school seven years later. They found that children with higher levels of externalizing behaviour problems at age three reported more loneliness at age 10. The results from this study suggested that children's behaviour problems influence their sense of belonging at

school. Externalizing behaviour has also been associated with lower levels of social acceptance for children with ASD (Jones & Frederickson, 2010).

Internalizing behaviour, which includes emotional symptoms of depression and anxiety, may also place individuals at risk for a poor social self-concept. Among typically developing children and adolescents there is a robust literature indicating that increased rates of anxiety and depression are associated with more negative social self-concepts (Spilt, van Lier, Leflot, Onghena, & Colpin, 2014), lower social competence (Bornstein, Hahn, & Haynes, 2010), greater peer rejection (Prinstein & Aikins, 2004), and poor friendship quality (Tipton, Christensen, & Blacher, 2013). Internalizing issues also seem to be linked with low levels of social acceptance for individuals with ASD. Mazurek (2013) found that self-reported loneliness was associated with increased depression and anxiety for 108 adults with ASD, after controlling for symptoms of ASD. Whitehouse, Durkin, Jaquet, and Ziatas (2009) similarly observed a negative correlation between the self-reported quality of friendships and self-reported depressive symptoms for 35 adolescents with Asperger's Syndrome. Specifically, best-friendships characterized by high levels of conflict/betrayal predicted higher depressive symptoms. Tipton and colleagues (2013) was the only group to interview 13-year-old adolescents with ID for internalizing issues and social self-concept, and in this subgroup, showed the negative correlation between internalizing behaviour problems and self-reported ratings of friendship quality (Tipton et al., 2013). Given the high rates of emotional and behavioural problems among individuals with DD throughout the lifespan (Benson & Aman 1999; Koritsas & Iacono, 2012; Lundqvist, 2013), it is critical to examine whether emotional

and behavioural problems are associated with social and physical self-concept in this population.

Involvement in adapted recreation and leisure activities such as sport participation is cited as an important context for experiencing physical, social, and emotional well-being, including healthy self-concept (Murphy & Carbone, 2008). Two aspects of sport participation are important to investigate when considering self-concept: diversity of sports (i.e., total number of sports) and the frequency of sport participation. Sampling numerous sports and physical activities during childhood is associated with prolonged engagement in and enjoyment of sport and physical activity and lower frequency of athletic injuries compared to early specialization for typically developing individuals (Côté, Horton, MacDonald, & Wilkes, 2009). In contrast, early specialization in one sport is associated with increased sport attrition (Côté, Baker, & Abernethy, 2007; Fraser-Thomas, Côté, & Deakin, 2008; Wall & Côté, 2007). Higher levels of frequency (i.e., hours per week and number of times per month) spent in leisure activities and school-based activities (e.g., sport) is also associated with greater developmental outcomes such as self-esteem and aspirational outcomes (Hansen & Larson, 2007; Marsh & Kliettman, 2002).

SO is one widely accessible adapted recreation program that has been associated with positive self-concept for individuals with DD. Dykens and Cohen (1996) examined self-concept in 104 elite SO athletes, ranging in age from 9 to 37 years, who participated in an international level competition (Team USA). They found that SO athletes had a more positive global self-concept than a comparison group of individuals with ID, matched on age, sex, IQ, and socio-economic status, who had not participated in SO.

Dykens and Cohen (1996) also found that the number of years in SO was the most powerful predictor of parent-reported athlete social competence. However, the authors did not examine the relationship between SO participation and physical or social self-concept. In a sample of 24 children with ID between the ages of 9 and 13, Gibbons and Bushakra (1989) found an improvement in social self-concept following a one and a half day SO track and field competition. After the competition, athletes reported more peer acceptance compared to pre-competition and to a nonparticipation comparison group. These authors did not examine physical self-concept, and neither of these studies focused on the most local level of involvement in SO, which has to do with participation outside of competitions (e.g., in regular SO training activities and events).

Weiss, Diamond, Demark, and Lovald, (2003) examined social self-concept and physical competence in a group of 97 SO athletes with ID between the ages of 9 and 43 years. The authors found that participation in SO, specifically the number of hours spent in training each week and the number of medals won, was associated with social self-concept. Similarly, the number of hours spent in training each week and the number of sports was associated with better physical competence. The authors did not examine aspects of physical self-concept beyond physical competence, such as physical self-worth, physical attractiveness, physical strength, or physical condition, nor did they include a global assessment of physical self-concept, which are necessary for a complete understanding of physical self-concept (Maiano et al., 2009).

### **Caregiver and Family Factors**

Caregivers and the family environment are two of the most formative contexts for global self-concept (Bronfenbrenner, 1977; Harter, 1999) and they play a key role in the

development of physical (Babkes & Weiss, 1999) and social (Howell et al., 2007) self-concept. Caregiver mental health problems appear to be related to global self-concept among typically developing individuals. Mothers with at least one episode of unipolar major depression are more likely to have a child with lower self-reported global self-concept than mothers without depression (Goodman, Adamson, Riniti, & Cole, 1994). The family climate and caregiver-child relationship are also critically related to self-concept. Ullrich-French and Smith (2006) examined how the parent-child relationship was associated with typically developing youths' physical self-concept, specifically, perceptions of competence in sport, in a study of 186 soccer athletes between the ages of 10 and 14 years of age. The authors found that more positive perceptions of parent-child relationship quality were associated with more positive physical self-concept (i.e., perceived competence in sport). There is also considerable research indicating that the caregiver-child relationship and family climate are associated with social functioning. Parents' expressed positive and negative affect, warmth, and responsiveness have been related to teacher and peer ratings of children's social acceptance and social competence in typically developing samples (Davidov & Grusec, 2006; Isley, O'Neil, & Parke, 1996; McDowell & Parke, 2009). In a study of 82 children with DD, Howell et al. (2007) found that family climate, as measured by the self-reported Family Environment Scale (Moos, 1974), was a significant predictor of child self-reported loneliness. Specifically, children from families with a more positive family climate at age three reported less loneliness at age 10.

Expressed emotion (EE) is one well-validated indicator of the emotional climate of the family and the quality of the parent-child relationship (Orsmond, Seltzer,

Greenberg, & Krauss, 2006), which may be particularly relevant to the study of self-concept. Two dimensions of EE include *criticism*, which captures feelings of negativity, and *emotional over-involvement* (EOI), which is reflective of extreme over-protectiveness or self-sacrifice on the part of the family member (Greenberg, Seltzer, Hong, & Orsmond, 2006). Caregivers are categorized as high, moderate, or low EE, which is a general rating that captures the caregiver's overall emotions and attitudes toward their child (Benson, Daley, Karlof, & Robison, 2011). EE was initially developed to examine how the family environment affects relapse rates for adults with schizophrenia; however, the high EE rating has been shown to be predictive of a number of different mental health and medical conditions in adults (e.g., Chambless, Bryan, Aiken, Steketee, & Hooley, 2001) and in children (e.g., Hamilton, Asarnow, & Tompson, 1999; Hirshfeld, Biederman, Brody, Faraone, & Rosenbaum, 1997; Peris & Baker, 2000; Steketee, Van Noppen, Lam, & Shapiro, 1998). In sum, children from families who are classified as high EE, high criticism, and/or high EOI are at risk for negative outcomes (Hooley & Gotlib, 2000).

Researchers are beginning to examine EE in families of individuals with DD (e.g., Beck, Daley, & Hastings, & Stevenson, 2004; Dossetor, Nicol, Stretch, & Rajkhowa, 1994; Greedharry, 1987; Lam, Giles, & Lavander, 2003). Results from these studies indicate that one quarter to one third of families are rated as high in criticism and/or EOI (Dossetor et al., 1994; Greedharry, 1987). Mothers of children with DD appear to show higher levels of EE compared to mothers of typically developing individuals, but lower than mothers of children with psychiatric disorders (Peris & Baker, 2000; Steketee et al., 1998). Beck et al. (2004) explored EE in 33 mothers of children with ID between the ages

of 4 and 14 years and found more behaviour problems in children whose mothers were rated as high EE than low EE. Another study of 75 mothers of children with ID ranging from 3 to 19 years of age found that high criticism was related to more severe externalizing behaviours as reported by parents cross-sectionally but not longitudinally (Hastings, Daley, Burns, & Beck, 2006). In adolescents and adults with ASD (aged 11 to 48 years) though, Greenberg et al. (2006) reported a longitudinal relationship between high EE and increased levels of maladaptive behaviour and more severe ASD symptoms over an 18-month period. Baker, Smith, Greenberg, Seltzer, and Taylor (2011) followed these same families over a seven year period and reported that an increase in maternal criticism over time predicted greater behaviour problems at the conclusion of the study.

To date, no study has examined how EE relates to the physical and social self-concept in individuals with DD. Preliminary research based on one study of children with ASD indicates that parental EE is associated with child social functioning (Benson, 2013). Benson (2013) found that maternal EE was a significant cross-sectional predictor of the number of playmates and group play participation based on parent report, although this study did not use self-reports of self-concept. This author also suggested that maternal EE may be implicated in the increase of child social difficulties over time.

### **Research Gaps and Current Study**

There are a number of potential predictors of physical and social self-concept that have yet to be examined in youth and young adults with DD. Age, sex, BMI, emotional and behavioural problems, caregiver mental health, family functioning, and EE are all understudied variables. Further, although studies have indicated that a relationship exists between self-concept and participation in SO for individuals with DD, these studies did

not examine different subdomains of physical self-concept and only one study examined participation outside of competitions. Finally, research has yet to examine the combined individual and family predictors of physical and social self-concept in youth and young adults with DD.

The purpose of this study was to investigate the individual and family correlates of physical and social self-concept for adolescents and young adults with DD involved in community level SO. The study addressed many of the limitations outlined above, by utilizing self-reports of physical and social self-concept and providing detailed information about individual and family factors. It is the first study to examine the individual and family predictors of social and physical self-concept for adolescents and young adults with DD involved in SO.

### **Hypotheses**

In terms of individual factors, we predicted that higher levels of physical and social self-concept would be related to being older, having a lower BMI, having fewer emotional and behavioural problems, and higher participation in sport. Males would have higher levels of physical self-concept and females would have higher levels of social self-concept. Caregivers with mental health issues, families with poor functioning, and caregivers who were classified as high EE would have athletes with lower physical and social self-concepts. Individual and family factors, together, would significantly predict the physical and social self-concept of adolescents and young adults with DD involved in SO.

## Method

### Participants

Participants included 51 caregivers and 51 athletes registered with Special Olympics Ontario. Athletes were between the ages of 12 and 22 (28 males and 23 females; age  $M = 16.98$ ,  $SD = 3.02$ ) and their Full Scale IQ ranged from 45 to 121 ( $M = 68.51$ ,  $SD = 18.86$ ) as measured by the Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II; Wechsler, 2011). Caregivers were between 35 and 71 years of age ( $M = 49.80$ ,  $SD = 6.95$ ) and 86.3% ( $n = 44$ ) identified as “White, Caucasian, Anglo, European Canadian.” Twenty percent ( $n = 10$ ) of athletes were living in single-parent households. All athletes were reported to have a DD through parent report of ID or ASD. Thirty-three percent ( $n = 17$ ) of the sample was reported to have a diagnosis of ASD. Youth were currently living with one or both parents (90.2%,  $n = 46$ ), with foster parents (3.9%,  $n = 2$ ), with grandparents (2%,  $n = 1$ ), or independently (2%,  $n = 1$ ) (2% were missing,  $n = 1$ ). Respondents had completed varying levels of educational attainment: high school degree or less (15.7%,  $n = 8$ ); college/trade/non-university diploma (27.5%,  $n = 14$ ); university degree (54.9%,  $n = 28$ ); 2% were missing ( $n = 1$ ). Forty-seven percent ( $n = 24$ ) of caregivers reported a total before-tax household income under \$100,000 (CAD) per year. Caregivers were also asked how well they were managing financially, ranging from 1 = *managing well* to 6 = *deep financial trouble* (National Centre for Social Research and Department for Work and Pensions, 2011), with 9.8% reporting some degree of financial struggle. Respondents were from remote (2 %,  $n = 1$ ), rural (9.8%,  $n =$

5), suburban (51.0%,  $n = 26$ ), and urban (33.3%,  $n = 17$ ) settings in Ontario (3.9%,  $n = 2$  were missing).

### **Procedure**

The current study is part of a larger project on sport participation for individuals with DD involved in SO. Caregivers of athletes registered in SO Ontario were invited to complete an online survey about the sport experiences of their athlete. Caregivers who filled out the survey were asked if they would be interested in participating in an in-person interview with their athlete. Of the caregivers who filled out the initial online survey, 317 (61.4%) agreed to be contacted for an in-person interview. A total of 60 caregivers and their athletes participated in the in-person interview. Interviewers consisted of Clinical Psychology graduate students, all of whom had previous training and experience working with individuals with DD. If an interviewer had any concerns about an athlete's level of comprehension, data for that participant were removed. Data were also eliminated if there was a noticeable pattern of acquiescence or unusual responses. Data from nine of the athletes were excluded due to inadequate comprehension (See Figure 2). The final sample ( $n = 51$ ) was compared to the original sample ( $n = 516 - 51 = 465$ ) on key demographic characteristics (See Table 1). There were no significant differences between the final sample and the original sample, except that athletes in the final sample played significantly more sports ( $M = 2.96$ ,  $SD = 1.69$  compared to  $M = 2.22$ ,  $SD = 1.41$ ) and played sports more frequently ( $M = 2.38$ ,  $SD = .73$  compared to  $M = 1.85$ ,  $SD = .81$ ),  $t(57) = 2.98$ ,  $p = .004$  and  $t(502) = 4.44$ ,  $p < .001$ , respectively. Caregivers provided informed consent (See Appendix A) and athletes provided informed assent (See Appendix B) in accordance with York REB standards for

individuals under the age of 16. All athletes provided informed assent regardless of age to keep procedures consistent for all participants. During the in-person visit, athletes completed the WASI-II, as well as a structured interview assessing physical self-concept, social self-concept, and emotional well-being while caregivers completed a paper-and-pencil survey in a separate room. Once the athlete interview concluded, caregivers completed the five minute interview using the Five Minute Speech Sample (FMSS) away from the athlete. Interviewers spent a total of approximately 60-120 minutes with caregivers and athletes. The project was approved by the York University Research Ethics Board.

## **Measures**

### **Individual Factors.**

***Demographic Information.*** Caregivers were asked to indicate their own age and ethnicity. They were also asked to indicate the age, sex, height, and weight of their athlete.

***Adaptive Behaviour.*** Caregivers completed the Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013), which was developed for use with parents of adolescents and adults with ASD and with ID (12 to 48 years of age) and measures an individual's independence in doing a variety of activities of daily living, such as "making his/her own bed" and "drinking from a cup." The W-ADL consists of 17-items which are rated on a three point scale: "*does not do at all,*" "*does with help,*" "*independent or does on own.*" Higher scores reflect greater level of functioning. The W-ADL is strongly correlated with the Vineland Adaptive Behaviour Scale Composite Score and Daily Living subscale ( $r = .78$  and  $r = .78$ , respectively; Maenner et al., 2013), demonstrating

strong criterion and construct validity. The internal consistency across samples with different disabilities ranges from good to excellent (Cronbach's  $\alpha = .88$  to  $.94$ ; Maenner et al., 2013) and was good in the current study (Cronbach's  $\alpha = .83$ ).

**Body Mass Index (BMI).** Caregivers provided the weight and height of each athlete. BMI was calculated by dividing the athlete's weight in kg by his/her squared height ( $\text{kg}/\text{m}^2$ ).

**Emotional and Behavioural Problems.** Emotional and behavioural problems were measured using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). The SDQ is a brief 25-item caregiver-report scale composed of five subscales: emotional symptoms, conduct problems, hyperactivity, peer problems, and prosocial behaviour. Total difficulties was computed by calculating an average of all the subscales except prosocial behaviour. Higher scores for all SDQ subscales correspond with more emotional and behavioural problems and higher scores for the prosocial behaviour subscale indicate more prosocial behaviour. Caregivers rated each item using a three-point scale: "not true," "somewhat true," "certainly true." The SDQ has adequate inter-rater and test-retest reliabilities, and internal consistency (Goodman, 2001). For example, the internal consistency of the SDQ subscales ranged from Cronbach's  $\alpha = .55$  to  $.80$  in a previous study using a sample of 260 children (6-12 years) with ID (Kaptein, Jansen, Vogels, & Reijneveld, 2008). For the current study, internal consistency was Cronbach's  $\alpha = .85$  for total difficulties, Cronbach's  $\alpha = .82$  for emotional symptoms, Cronbach's  $\alpha = .78$  for conduct problems, Cronbach's  $\alpha = .78$  for hyperactivity, Cronbach's  $\alpha = .62$  for peer problems, and Cronbach's  $\alpha = .82$  for prosocial behaviour. Research suggests that

the SDQ is a valid measure of the mental health needs of children and adolescents with intellectual disability (Beck et al., 2004; Emerson, 2005).

***SO Participation.*** Caregivers were asked, on average, in the last 12 months, how often their athlete participated in Special Olympics sports (“*never,*” “*a few times a year,*” “*once per month,*” “*2-4 times per month,*” “*once a week,*” “*several times a week*”).

Caregivers were also asked; “In the last 12 months, what SO sports has your child participated in?” Caregivers selected “*Yes*” or “*No*” for 19 different eligible sports.

### **Caregiver and Family Factors.**

***Caregiver Mental Health.*** One caregiver for each athlete completed The Depression Anxiety Stress Scale (DASS-21; Lovibond & Lovibond, 1995) as a measure of caregiver mental health. The DASS-21 includes 21 items, each of which is rated on a four-point scale (“*never,*” “*sometimes,*” “*often,*” “*almost always,*”), and three subscales: depression, anxiety, and stress, with higher scores reflecting more mental health issues. The scale has been shown to have high internal consistency and to discriminate between clinical and community samples (Lovibond & Lovibond, 1995). Internal consistency for the current study was good for depression (Cronbach’s  $\alpha = .89$ ), stress (Cronbach’s  $\alpha = .85$ ), and anxiety (Cronbach’s  $\alpha = .71$ ).

***Family Functioning.*** Family functioning was measured using The General Functioning Scale of The McMaster Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983). The General Functioning Scale contains 12 items, which caregivers rated using a four point scale (“*strongly agree,*” “*agree,*” “*disagree,*” “*strongly disagree*”). Higher scores on the scale correspond with better family functioning. The FAD has adequate test-retest reliability, and convergent and discriminant validity

(Friedmann et al., 1997; Wenniger, Hageman, & Arrindell, 1993) and has been employed in studies of families with children with DD (e.g., Herring et al., 2006). The internal consistency for the FAD was excellent: Cronbach's  $\alpha = .90$ .

***Expressed Emotion.*** Expressed Emotion was measured using instructions based on the Five Minute Speech Sample (FMSS; Magaña et al., 1986). Examiners asked caregivers to speak for five minutes, telling them what kind of person their athlete is and how the two of them get along together. The speech samples were recorded, transcribed, and then coded based on the detailed Autism-Specific Five Minute Speech Sample (AFMSS) coding manual developed by Daley and Benson (2008). The AFMSS coding scheme made adjustments to the FMSS coding scheme to make it more applicable to families of individuals with DD. The AFMSS uses the same coding categories, but adds two additional dimensions: warmth and positive comments. The speech samples were given ratings for the initial statement made by the caregiver (coded positive, neutral, or negative), the caregiver's relationship with the child (coded positive, neutral, or negative), the level of warmth expressed by the caregiver (coded high, moderate, or low), and the emotional over-involvement with the child (coded high, moderate, or low). The speech samples were also coded using two frequency counts: the total number of critical comments expressed by the caregiver about the child and the total number of positive comments made by the caregiver about the child. Finally, the speech samples were also given an overall rating of caregiver AFMSS-EE based on the assessment of all six AFMSS-EE components. Initial statement and EOI were removed from analyses due to lack of variability, AFMSS-EE was included because it provided an overall summary rating. Research demonstrates that this coding scheme for the AFMSS has adequate

internal consistency, and good to excellent inter-rater and code re-code reliability and acceptable validity (Beck et al., 2004; Benson et al., 2011). Inter-rater reliability was assessed on 17 randomly selected speech samples by two different raters, and code-recode reliability was assessed using the same 17 randomly selected speech samples coded on two separate occasions approximately one month apart. In the present study, recode-recode reliability for the six EE components assessed by the AFMSS ranged from .70 to 1.00, while inter-rater reliabilities ranged from .73 to 1.00 (See Table 2).

### **Dependent Variables.**

***Social and Physical Self-Concept.*** Social self-concept was assessed using a lab-developed measure based on items used in past research with youth with ID. Seven items were taken from Riggen and Ulrich (1993) and Harter and Pike (1984), which explored athletes' perceptions of social acceptance: "I am popular (a favourite) with others my age," "I wish that people liked me," "I usually do things with lots of people," "I am among the last to be chosen for activities," "It's easy for me to make friends," "I don't think I am very well liked by others on my team," "I have a lot of friends." Riggen and Ulrich (1993) used these items in a structured alternative format with a group of individuals with DD involved in Special Olympics and found that the items had adequate test-retest reliability and internal consistency. Physical Self-Concept was measured using The Physical Self-Inventory-Very Short Form-Intellectual Disability (PSI-VSF-ID) (Maiano et al., 2009), which was adapted from the very short form version of the Physical Self-Inventory (PSI; Ninot et al., 2000). The PSI-VSF-ID consisted of 12 items and six subscales: global self-concept (GSC), physical self-worth (PSW), sport competence (SC), physical attractiveness (PA), physical strength (PS), and physical condition (PC) (See

Appendix C). The examiner read each item aloud and asked, “*How much is that like you?: Not at all like you, very little like you, somewhat like you, enough like you, a lot like you, or entirely like you*” Athletes responded by pointing to a graphical answer-scale adapted from Maiano et al. (2009) (See Appendix D). Higher scores reflect better social and physical self-concept. The internal consistency for social self-concept was acceptable (Cronbach’s  $\alpha = .63$ ). Maiano et al. (2009) provided evidence for the factorial validity and reliability, as well as the factorial invariance across sex, age, type of school placement, and ID level of the PSI-VSF-ID using the graphical response scale format (Maiano et al., 2009). Internal consistencies for the current study ranged from good to excellent: PSI overall mean (Cronbach’s  $\alpha = .81$ ), PSW (Cronbach’s  $\alpha = .82$ ), PC (Cronbach’s  $\alpha = .73$ ), SC (Cronbach’s  $\alpha = .68$ ), PA (Cronbach’s  $\alpha = .65$ ). Subscales were excluded from analyses if their internal consistencies were less than Cronbach’s  $\alpha = 0.6$ : GSC (Cronbach’s  $\alpha = .03$ ) and PS (Cronbach’s  $\alpha = .55$ ).

### **Data Analysis Plan**

Independent-samples *t*-tests were conducted to examine whether males have higher ratings on physical and social self-concept than females. Pearson product-moment correlations were conducted to examine whether age, BMI, IQ, emotional and behaviour problems, SO Participation, EE, Caregiver mental health, family functioning, and financial management were related to physical and social self-concept. Multiple linear regressions were employed to examine whether including individual and family variables together predicted a significant amount of variance in physical and social self-concept.

## **Results**

### **Preliminary Exploratory Analysis**

***Missing Data Analysis.*** Frequency and descriptive analyses were conducted to detect missing and erroneous data points. Missing data are summarized in Table 3. All multivariate analyses were conducted listwise so as to only include individuals with complete data.

***Multicollinearity.*** Collinearity was also examined for independent variables. All of the bivariate correlations were acceptable (less than .90) for including in multivariate analysis (Tabachnick & Fidell, 2007). All of the variance inflation factors were less than 2.

### **Assumptions For Correlations**

An assumption of Pearson's correlation is that the sampling distribution is normally distributed. However, since many of the variables were not normally distributed they were checked using a non-parametric bootstrap. The same pattern of results emerged.

### **Assumptions For Regressions**

***Independent Errors.*** The Durbin-Watson test was used to examine whether the residuals in the models were independent. The Durbin-Watson values were between one and three, which suggests that the residuals were uncorrelated.

***Homoscedasticity and Linearity.*** Homoscedasticity was examined by plotting the standardized residuals against the standardized predicted values of the dependent variable based on the model. These plots indicated that at each level of the predictor variables, the variance of the residual terms remained constant. They also indicated that the assumption of linearity was met.

***Normally Distributed Errors.*** Histograms and normal P-P plots indicated that the residuals were normally distributed.

***Outliers and Influential Statistics.*** No Cook's distances were above 1, so we could assume that none of the cases were exerting undue influence on the models. All of the Mahalanobis distances were less than 11 which suggested that there were no multivariate outliers.

### **Descriptive Analyses**

Means, standard deviations, and ranges of scores for all variables are presented in Table 4. Table 5 presents the descriptive statistics for the AFMSS. Almost no variability was observed for EOI, with 98% of the sample classified as low EOI. For the AFMSS-EE, none of the sample was classified as high EE, 25.5 % as moderate (borderline) EE, and 74.5 % as low EE.

### **Main Analyses**

Pearson's product-moment correlations were conducted to determine if there were significant associations between predictor variables and social and physical self-concept variables. Independent-means *t*-tests were used to examine sex differences in social and physical self-concept.

#### **Social Self-Concept**

***Individual Factors.*** There was a trend towards female participants reporting higher levels of social self-concept ( $M = 3.55, SD = .81$ ) compared to male participants ( $M = 3.05, SD = 1.08$ ),  $t(48) = -1.82, p = .08$ . Five significant correlations emerged between predictor variables and social self-concept (See Table 6). There was a positive relationship between child age and social self-concept,  $r(48) = .29, p = .04$ . Total

difficulties and peer problems were negatively associated with social self-concept,  $r(43) = -.31, p = .04$  and  $r(46) = -.29, p = .05$ , respectively. Total sports and SO participation frequency were positively related to social self-concept,  $r(47) = .32, p = .03$  and  $r(47) = .36, p = .01$ , respectively. Three variables (child age, total difficulties, and SO participation) were entered into a regression. Total sports was excluded from the regression because it was strongly correlated with the frequency of sport participation,  $r(48) = .68, p < .001$ , and peer problems was also excluded from the regression because it was strongly correlated with the total difficulties,  $r(44) = .72, p < .001$ . The overall model was significant  $F(3, 40) = 3.65, p = .02$ , accounting for 22% of the variance in social self-concept (See Table 7). There were trends toward total difficulties and the frequency of sport participation being significant predictors at the level of  $p < .10$ ,  $\beta = -.28, p = .06$  and  $\beta = .25, p = .10$ , respectively.

***Family Factors.*** None of the family factors were related to social self-concept.

#### **Physical Self-Concept: PSI-Physical Competence Subscale**

***Individual Factors.*** There were no significant sex differences for any of the PSI subscales and none of the PSI subscales was significantly correlated with the predictor variables, except for the physical condition subscale (See Table 8). Child age and BMI were negatively associated with physical condition,  $r(48) = -.43, p = .002$  and  $r(46) = -.47, p = .001$ , respectively. These predictors were entered into a regression that accounted for 29% of the variance in PSI-physical condition,  $F(2, 45) = 8.98, p = .001$ . BMI was a significant predictor  $\beta = -.31, p = .04$ , accounting for 7% of the variance in PSI- physical condition. There was a trend towards child age being a predictor at the level of  $p < .10$ ,  $\beta = -.30, p = .05$ , accounting for 6% of the variance in PSI- physical condition.

***Family Factors.*** None of the family factors were related to physical self-concept.

### **Discussion**

Despite the existence of several studies investigating the social and physical self-concept of individuals with DD involved with SO, few studies have examined specific individual and family predictors and their relationship to social and physical self-concept. To our knowledge, the current study is the first to examine the individual and family predictors of physical and social self-concept in a population of youth and young adults with DD involved in SO using self-report measures. Self-concept is a critical variable for understanding a person's self-perceptions of competence and personal characteristics. We examined the self-concept of athletes involved in SO, an area of inquiry that tends to be overlooked in the field of DD. Glidden et al. (2011) demonstrated that parents of athletes in SO tend to inflate the benefits of being involved in SO, compared to athlete self-report, so examining self-concept from the athletes' perspectives rather than using proxy reporting is particularly important. We hypothesized that individual factors (e.g., age, sex, BMI, emotional and behavioural problems, and participation in SO) would be significantly related to physical and social self-concept. Social self-concept was significantly predicted by age, emotional and behavioural problems, and SO involvement in a combined model, and physical self-concept was significantly related to age and BMI. We also predicted that family factors (e.g., caregiver mental health, family functioning, and EE) would be significantly related to physical and social self-concept; however none of the family factors were related to either physical or social self-concept. Finally, we hypothesized that individual and family factors, together, would significantly predict physical and social self-concept. We were unable to test this hypothesis because none of

the family factors were significant, leaving regressions to identify only the significant individual predictors.

### **Social Self-Concept**

The results of the current study supported the hypotheses that being older, having fewer emotional and behavioural problems and having higher levels of SO participation (total number of sports and frequency of involvement in SO) would be positively associated with social self-concept. These results are consistent with the extant literature that provides preliminary evidence for the association between individual factors such as age (e.g., Marsh, 1989), total difficulties (e.g., Howell et al., 2007), SO involvement (e.g., Dykens & Cohen, 1986) and social self-concept.

The multiple regression analysis indicated that total difficulties and SO participation frequency were independently able to account for a proportion of the variance in social self-concept. What stands out from this study is the relative importance of total difficulties as a predictor of social self-concept for athletes involved with SO. This finding suggests that athletes with more total difficulties report feeling less socially accepted, which is consistent with previous literature examining the relationship between problem behaviours and social acceptance. For typically developing individuals, externalizing behaviour is associated with peer rejection, which in turn is associated with loneliness (Pederson, Vitaro, Barker, & Borge, 2007). For individuals with DD, difficulty with behaviour regulation is associated with peer rejection (Bellanti & Bierman, 2000), and Howell et al. (2007) demonstrated that children with lower levels of externalizing behaviour problems at age 3 reported less loneliness at age 10. The current study extends these findings by demonstrating the relationship between total difficulties (which

includes externalizing and internalizing issues) and social self-concept for adolescents and young adults with DD. An implication of this finding is the importance of regulating problem behaviours for individuals with DD. Therefore, interventions aimed at improving social self-concept should also target problem behaviours.

The frequency of SO Participation was not a significant predictor of social self-concept; however, there was a trend toward significance, suggesting that higher levels of sport frequency each month is associated with athletes reporting higher social self-concept. Theoretically, participation in sport increases contact with peers and provides opportunities for athletes to form friendships and develop a positive social identity (Dykens & Cohen, 1996), and, empirically, participation in physical activities has been linked with positive self-concept. Weiss et al. (2013) demonstrated that SO participation is associated with higher levels of peer acceptance. The current study sought to extend this research by looking at the frequency of SO participation in the previous year.

None of the family variables (e.g., caregiver mental health issues, family functioning, and expressed emotion) were related to athlete reports of their self-concept. This contrasts with some earlier work with individuals with DD, demonstrating that healthy family climate (i.e., more cohesive and expressive relationships and less family conflict) during early childhood (age three) was a unique predictor of children's perceptions of social belonging at age 10 (Howell et al., 2007). One explanation for why family factors were not significantly related to social self-concept in the current study is that our sample involved adolescents and young adults, ranging in age from 12 to 21. It is possible that family factors are stronger predictors of social self-concept during early childhood than they are during adolescence and young adulthood, which is characterized

by individuation and autonomy-striving (Steinberg & Morris, 2001; Silverberg & Steinberg, 1990).

Another possible explanation for why family factors were not significantly related to social self-concept is that there was not a lot of variability in the AFMSS scores. Overall, the descriptive statistics for the AFMSS in the current study were consistent with the descriptive findings conducted by Benson et al. (2011). More specifically, the proportion of positive, neutral, and negative responders for the relationship, warmth, and EOI scales in the current study were similar to what was previously reported (see Table 5). The average number of positive comments made by caregivers in the current sample was also similar to what was found by Benson et al. (2011), whereas the number of negative comments made by caregivers in the current study was lower than previously published. In both studies, few initial statements were coded as negative (2.9% in the Benson et al. (2011) study and 0% in the current study). None of the participants in the current study were coded as high EE, whereas 9.6% of participants in Benson et al. (2011) were coded as such. Participants in the Benson et al (2011) study were recruited from a variety of public and private schools, multi-system special needs programs, and autism service organizations, whereas the participants in the current study were drawn from SO registration lists. Because the current participants were embedded within a network of SO social support, these families may have better family functioning (i.e., less EE) than families in the general public; however, this has yet to be examined empirically.

### **Physical Self-Concept**

Age and BMI emerged as two main correlates of one of the subdomains of physical self-concept (physical condition) and none of the other variables related to any

aspect of physical self-concept. Age was significantly negatively related to physical condition, which was opposite to what was hypothesized. For typically developing individuals, physical self-concept decreases in early and middle adolescence and then increases during late adolescence and early adulthood (Marsh, 1989). The results of the current study suggest that for individuals with DD, a negative relationship between age and physical self-concept continues through late adolescence and early adulthood.

The direction of the relationship between age and physical self-concept is different for individuals with DD compared to typically developing individuals, and it may be that another variable, such as sense of mastery, is moderating this relationship. In a longitudinal study examining the development of self-esteem in typically developing individuals from age 14 to 30, Erol and Orth (2011) demonstrated that increases in self-esteem were explained by participants' appraisal of mastery. In children with DD, mastery motivation is often delayed compared to typically developing peers (Gilmore, Cuskelly, & Hayes, 2003), which could negatively impact the development of positive self-concept. Longitudinal research is needed to test this hypothesis.

As predicted, BMI was also significantly negatively correlated with physical condition, and the multiple regression analysis indicated that child age and BMI independently accounted for variance in physical condition, with BMI accounting for more variance than age. Similarly, Petrie et al. (2010) found a negative relationship between BMI and physical self-concept in a sample of typically developing boys and girls in grades six through eight. The measure of physical self-concept in the Petrie et al. (2010) study specifically asked about strength and endurance, which is similar to the physical condition subscale of the current study (e.g., "I can run a long time without

tiring” and “I can run ten times around the basketball course without stopping”). These results suggest that athletic endurance is better for individuals with low BMI compared to individuals with high BMI. The finding that age and BMI were the only individual factors correlated with any of the physical self-concept subscales indicates that, for athletes involved with SO, physical qualities are linked more closely to physical self-concept than other individual variables such as total difficulties, and SO participation.

None of the family factors were related to any of the physical self-concept subscales, which may be explained, in part, by limited variability in EE. While no previous research has investigated the relationship between family and physical self-concept among DD youth, this finding is similar to the results of Jowett and Cramer (2010), who investigated the relationship between typically developing athletes’ perception of their relationship with parents and coaches and their physical self-concept. Correlational analyses indicated that physical self-concept was unrelated to athletes’ perception of the relationship quality with their parents, but was related to athletes’ perception of the relationship quality with their coach. Other research has reported a relationship between the quality of the parent-child relationship and typically developing athletes’ physical self-concept (Ullrich-French, & Smith, 2006). This association may depend on participant age. Participants in Ullrich-French and Smith’s (2006) study were between 10 and 14 years of age, which according to Wylleman et al. (2007), corresponds with the initiation stage of parental involvement in sport, a stage when parents are theorized to have the most influence on their child’s involvement in sport. In the current study and in the study by Jowett and Cramer (2010), athletes consisted of adolescents and young adults, so they may have moved beyond the initiation stage into the developmental

stage, and in both of these studies, the child-parent relationship was playing a less influential role. Ullrich-French and Smith (2006) also used athlete report of mother-child and father-child relationship quality, rather than a parent report or observational measure, which could yield different results.

### **Limitations**

Several limitations of the current study should be noted. First, the participants represent a specific subgroup within DD: athletes involved in SO between the ages of 12 and 22 with Full Scale IQ scores ranging between 45 and 121. It is possible that this subgroup of participants had better social and physical self-concepts and better family climates (i.e., lower EE) compared to families involved in SO who did not participate in the study and compared to families of children with DD who are not involved in SO. However, family functioning was not significantly different between the 51 participants in the current study compared to the original sample of participants who completed the online survey (See Table 1). Of note, IQ was not related to any of the study variables and athletes were only included if it was clear that they understood the questions and could clearly communicate a response. Examining this subgroup of individuals with DD is worthwhile because it helps us to understand the specific profile of athletes involved in SO. Sport frequency and the total number of sports were used as indicators of sport participation; however, other variables such as the number of medals received or quality of sport involvement would be worth examining. Future research should examine these sport variables and their relationship to physical and social self-concept. Another limitation is that the results are correlational and, it is likely that there is a bidirectional relationship between individual and family factors and social and physical self-concept.

In particular, research on social self-concept suggests a bidirectional relationship between total difficulties and social self-concept (e.g., Gilmore & Cuskelly, 2014). Additionally, there was the issue of a small sample, which meant that the power for detecting medium effects was 0.71 and the power for detecting small effects was 0.17. Even with a small sample, the study highlights important variables that should be the focus of future inquiry. Caregivers also primarily consisted of mothers, and research shows that mothers and fathers, and potentially other caregivers respond differently to the experience of parenting a child with DD (Hastings et al., 2005). The analyses of the current study included a large number of comparisons, which can increase the probability of making Type 1 errors; however, given our low power, the exploratory nature of the study, and small effects, we did not want to employ a correction that would unduly increase the rate of Type 2 errors.

### **Future studies**

Studying the self-concept of individuals with DD using self-report is a relatively new area of research, and this study highlights the need for more research on the self-concept of individuals with DD more generally and those who are involved in SO specifically. A potential area of future research is examining social and physical self-concept longitudinally. For typically developing individuals, we know that there is a decline in self-concept during early and middle adolescence (Klomsten, Skaalvik, & Espnes, 2004; Marsh, 1989; Wigfield & Eccles, 1994) and then an increase in positive self-concept during late adolescence and early adulthood (Marsh, 1989), but we do not know if a similar trajectory exists for individuals with DD.

Despite the lack of significant findings with regard to the family factors, there is precedence for examining the association between the quality of social relationships and self-concept (e.g., Howells et al., 2007). It will be critical for future research to examine the broader social network (e.g., relationship with coaches, friends, peers) for individuals with DD and use multiple methods (e.g., parent report, athlete report, and behavioural coding). Another avenue of future research is to examine the experience of mothers and fathers separately.

This study highlighted an important connection between total difficulties and social self-concept for individuals with DD, and an interesting avenue of research would be to examine how the self-report of behaviour problems and mental health issues relates to social self-concept. The findings of the current study also shed light on the relationship between BMI and physical self-concept, specifically physical condition. It is important that future research look more closely at how BMI is related to other aspects of physical self-concept such as body satisfaction. Another avenue of research is to examine physical disability and/or chronic health conditions and how they are associated with physical self-concept.

## **Conclusion**

The current study demonstrated associations previously unexplored related to the individual and family predictors of physical and social self-concept for individuals with DD. Specifically, this is the first study to examine the individual and family predictors of physical and social self-concept for individuals with DD involved in SO. Much remains unknown about the physical and social self-concepts of individuals with developmental disabilities. In some ways the self-concept of individuals with DD mirrors the self-

concept of typically developing individuals, and in other ways they differ. More work is needed to elucidate these similarities and differences to better understand and promote the positive self-concept of individuals with DD.

Study 2: The predictors of emotional well-being for adolescents and young adults with  
DD involved in Special Olympics

Quality of life is an important area of inquiry in the field of DD. Quality of life for individuals with DD encompasses their external objective life experiences as well as their subjective internal states (Dykens, 2006; Perry & Felece, 2002), consisting of eight key domains: physical well-being; social inclusion; interpersonal relationships; emotional well-being; material well-being; personal development; self-determination; and rights (Schalock, 2004). Emotional well-being is an area of particular concern when considering the quality of life of individuals with DD, as research indicates that this population experiences lower levels compared to typically developing individuals throughout the lifespan (Bhaumik et al., 2008). Emotional well-being is a subjective and global judgment of life experiences, and reflects an appraisal of life satisfaction, positive affect, and the absence of negative affect (Emerson & Hatton, 2008). In contrast to emotional well-being, the term psychopathology refers to diagnosable emotional and behavioural problems, typically assessed in individuals with DD using parent or caregiver completed checklists or interviews rather than self-report (e.g., Brereton, Tonge, & Einfeld, 2006). In other words, emotional well-being is distinct from psychopathology in that it is a subjective construct based on the self-report of positive and negative emotional states. The two constructs, however, are related because individuals who experience psychopathology typically have lower levels of emotional well-being (Stancliffe, Lakin, Taub, Chiri, & Byun, 2009).

There is a need to examine the emotional well-being of individuals with DD using self-report rather than proxy report (e.g., Glidden et al., 2011). An understanding of the

predictors of emotional well-being for individuals with DD will help service providers and policy makers identify the support needs of individuals with DD. Drawing from Bronfenbrenner's ecological framework for understanding human development (Bronfenbrenner, 1977), the purpose of the current study was to investigate the individual and family correlates of emotional well-being for adolescents and young adults with DD involved in SO.

### **Individual Factors**

To our knowledge, only one study has examined the individual characteristics that are associated with the emotional well-being of individuals with DD: Emerson and Hatton (2008) investigated the relationship between personal characteristics of individuals with DD and five indicators of emotional well-being. They found that age was positively associated with indicators of positive emotional well-being (happiness and confidence). This finding is consistent with research that has investigated the relationship between age and psychopathology. One of the most consistent findings is the significant negative association between age and symptoms of hyperactivity and/or conduct disorder (Hastings, Beck, Daley, & Hill, 2005; Stores, Stores, Fellows, & Buckley, 1998). For instance, in a study of 338 children between the ages of 4 and 18 with ID, younger children were rated as having more attention deficit/hyperactivity symptoms than older children (Brown, Aman, & Haverkamp, 2002). Borthwick-Duffy, Lane, and Widaman (1997) also found a negative association between age and internalizing scores from the parent reported Child Behaviour Checklist (Achenbach, 1991). Emerson and Hatton (2008) identified sex as a correlate of some indicators of emotional well-being. Women scored higher on indicators of positive affect (e.g., happiness) and negative affect (e.g.,

sad/worried, left out) compared to men. Sex also appears to be relevant to psychopathology with several studies demonstrating a higher incidence of externalizing issues among males with ID, including higher rates of behaviour problems (Emerson, 2003a), conduct problems (Emerson, 2003b), disruptive behaviour, and self-absorbed ratings (Hastings & Mount, 2001), whereas higher incidences of depression (Heiman, 2001) and anxiety (Einfeld et al., 2006) have been found for females with ID.

Based on research investigating the risk factors and correlates of psychopathology, other important individual factors that are likely related to emotional well-being include intellectual functioning, BMI, and emotional and behavioural problems (Witwer & Lecavalier, 2008). In terms of intellectual functioning, individuals with milder impairments are more likely to express themselves verbally than those with severe impairments, and have symptoms that parallel those of typically developing children (Witwer & Lecavalier, 2008). Individuals with milder ID tend to have higher rates of disruptive and emotional disorders and also show more improvements in symptoms over time than individuals with more severe ID (Einfeld et al., 2006). In contrast, individuals with severe ID display higher rates of stereotypy, self-injury, and social isolation, and they are less likely to show improvement over time compared to individuals with mild ID (Brown et al., 2002; Chadwick, Kusel, Cuddy, & Taylor, 2005; Chadwick, Piroth, Walker, Bernard, & Taylor, 2000). There is a connection between BMI and symptoms of depression for typically developing adolescents (Goodman & Whitaker, 2002; Pine, Goldstein, Wolk, & Weissman, 2001), with higher BMI associated with more symptoms of depression. With regard to emotional and behavioural problems, there is a strong body of research to suggest that individuals with ID who display challenging

behaviour and/or a psychiatric diagnoses report lower levels of emotional well-being (e.g., Stancliffe et al., 2009), and those who have more contact with friends (i.e., more prosocial behaviour) self-report higher levels of emotional well-being (Emerson & Hatton, 2008).

Special Olympics (SO), an international sporting organization, provides athletic training and competitions for children and adults with DD. Over 4.5 million athletes with DD are involved with SO in over 170 countries worldwide (Special Olympics, 2015a). A number of studies have found a relationship between SO participation and positive psychosocial outcomes for athletes and their parents (Dykens & Cohen, 1996; Farrell, Crocker, McDonough, & Sedgwick, 2004; Gibbons & Bushakra, 1989; Goodwin, Fitzpatrick, Thurmeier, & Hall, 2006; Mactavish & Schleien, 2004; Weiss & Bebko, 2008; Weiss et al., 2003), making it a useful program through which to explore emotional well-being, although to date, only one paper has done so (Glidden et al., 2011). Specifically, Glidden and colleagues (2011) investigated the benefits of athletic participation for individuals with DD as perceived by both athletes and their parents, conducting interviews with 34 SO sailing/kayaking athletes and their parents at a regional SO competition and 12 months later by telephone. During the initial interview, athletes and their parents were asked about well-being when at/not at sailing/kayaking events, and found that SO participation was associated with positive outcomes according to parents and athletes. Specifically, they found that parents and athletes endorsed greater levels of athlete happiness and more positive feelings during sailing/kayaking participation compared to when not participating in sailing/kayaking (e.g., “When you are (here now at/not at) sailing/kayaking. How do you mostly feel?”). The Glidden et al. (2011) study

was limited in that they only interviewed athletes who were involved in sailing/kayaking, and the majority of the participants in the study were older than 22 years (range = 12 to 49 years). Among typically developing individuals, diversity of sport experiences (i.e., total number of sports) is associated with positive outcomes such as prolonged engagement in and enjoyment of sport (Côté et al., 2009), and a higher frequency of involvement in sport is related to positive developmental outcomes including self-esteem (Hansen & Larson, 2007; Marsh & Kliettman, 2002).

### **Caregiver and Family Factors**

Caregiver mental health and family functioning have integral roles to play in fostering child emotional well-being and mental health. For instance, one of the most consistent findings in the literature is that caregiver mental health problems are associated with psychopathology in children with DD (e.g., Dekker & Koot, 2003; Emerson, 2003b; Hastings et al., 2006; Hatton & Emerson, 2004; Tonge & Einfeld, 2003) and those without (e.g., Pilowsky, Wickramaratne, Nomura, & Weissman, 2006). Researchers have also found an association between family functioning and child psychopathology using measures such as the McMaster Family Assessment Device (FAD; Epstein et al., 1983; Byles, Byrne, Boyle, & Offord, 1988), a caregiver report measure of family functioning (Emerson 2003b; Tonge & Einfeld, 2003, Wallander, Dekker, & Koot, 2006). Emerson (2003a) demonstrated that children were more likely to have an emotional disorder of any type, or an anxiety disorder specifically, when their family was characterized by more “unhealthy” functioning on the FAD. Parents who used more punitive strategies were more likely to have children with any emotional disorder and specifically a conduct disorder (Emerson, 2003a).

Measuring expressed emotion (EE) using the Five Minute Speech Sample (FMSS; Magana et al., 1986) is another way of examining family climate. EE is measured by asking the family caregiver to give a five minute speech sample about his or her child. The speech sample is recorded, transcribed, and then coded along a number of different dimensions and provides a general rating of high, moderate, or low EE based on the caregiver's overall emotions and attitudes toward their child (Benson et al., 2011). A growing number of studies have identified a connection between caregiver EE and child problem behaviours. For example, Beck et al. (2004) conducted a study with 33 mothers who had a child with ID and a child without disabilities between the ages of 4 and 14. They found that mothers had significantly higher EE toward the child with an ID compared to the child without a disability, and mothers rated as high EE had children with more behaviour problems than mothers rated as low EE. High EE based on the FMSS has been related to more severe child externalizing behaviours cross-sectionally in a sample of mothers with children with an ID (Hastings et al., 2006), and longitudinally in mothers of adolescent and adult children with ASD (Baker et al., 2011; Greenberg et al., 2006).

Research indicates that socio-economic status is related to emotional well-being in individuals with DD. In a study of socio-economic position and the emotional well-being of 1,273 adults with ID, Emerson and Hatton (2008) found that indicators of socio-economic position (e.g., whether the parent was in paid employment, overall neighborhood deprivation quintile, and economic hardship) were significantly related to participant emotional well-being. Emerson and Hatton (2007) also found that social disadvantage (e.g., single parent family, income poverty, and exposure to two or more

negative life events) was associated with higher rates of emotional disorders and conduct disorder (e.g., oppositional defiant disorder, socialized conduct disorder) among children with and without ID.

### **Gaps in Research**

Researchers have yet to examine whether age, sex, intellectual functioning, BMI, emotional and behavioural problems, prosocial behaviour, caregiver mental health, family functioning, and expressed emotion are related to emotional well-being in individuals with DD involved with SO, and we do not know if there is a relationship between SO participation (in terms of sport diversity and frequency of involvement) beyond sailing/kayaking, and emotional well-being for youth. With the exception of Emerson and Hatton (2008) and Glidden et al. (2011), the majority of research in this field has relied on proxy reporting, and focused on mental health problems instead of emotional well-being. While proxy reporting can be a valuable source of information, there are important concerns about its reliability and validity when measuring the internal states of individuals with DD (Perry & Felce, 2002; McGillivray et al., 2009; Perkins, 2007). In fact, Cummins (2002) argues that emotional well-being should not be measured via proxy, since it requires knowledge of another person's internal state. The studies that did use self-report measures (e.g., Emerson & Hatton, 2008; Glidden et al., 2011) are limited in that their samples were composed of only adults with DD, so research is needed to examine the correlates of emotional well-being specifically for adolescents and young adults. The aim of the current study was to investigate the individual and family correlates of emotional well-being for adolescents and young adults with DD involved in SO.

## Hypotheses

For individual factors, we expected that higher levels of emotional well-being would be related to being older, being female, having lower BMI, having higher levels of intellectual functioning, fewer emotional and behavioural problems, more prosocial behaviour, and higher levels of SO involvement (total sports and frequency of participation). At the level of the family, we hypothesized that higher emotional well-being would be associated with better caregiver mental health (i.e., less stress, anxiety, and depression), better family functioning, less EE, and better financial management. Finally, it was hypothesized that individual and family variables together would significantly predict the emotional well-being of adolescents and young adults with DD.

## Method

### Participants

Fifty-one caregivers and 51 athletes from SO Ontario participated in the study. Athletes were between 12 and 22 years of age (28 males and 23 females; age  $M = 16.78$ ,  $SD = 3.02$ ) and their IQ ranged from 45 to 121 ( $M = 68.51$ ,  $SD = 18.86$ ), as measured by the Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II; Wechsler, 2011). Caregivers were between 35 and 71 years of age ( $M = 49.80$ ,  $SD = 6.95$ ) and 86.3% ( $n = 44$ ) and identified as “White, Caucasian, Anglo, European Canadian.” Mothers (78.4%,  $n = 40$ ), fathers (11.8%,  $n = 6$ ), foster parents (3.9%,  $n = 2$ ), one grandparent (2.0%), and an aunt with full custody (2.0%) (2% were missing,  $n = 1$ ), participated in the study. Most of the caregivers were married (76.5%,  $n = 39$ ). All athletes were reported to have a DD, through caregiver report of ID or ASD. Thirty-three

percent ( $n = 17$ ) of the sample was reported to have an ASD. Youth were currently living with one or both parents (90.2%,  $n = 46$ ), with foster parents (3.9%,  $n = 2$ ), with grandparents (2%,  $n = 1$ ), or independently (2%,  $n = 1$ ) (2% were missing,  $n = 1$ ). Caregiver respondents had varying levels of educational attainment: high school degree or less (15.7%,  $n = 8$ ); college/trade/non-university diploma (27.5%,  $n = 14$ ); university degree (54.9%,  $n = 28$ ) (2.0% were missing,  $n = 1$ ). Forty-seven percent ( $n = 24$ ) of caregivers reported a total before-tax household income under \$100,000 (CAD) per year. Caregivers were also asked how well they were managing financially, ranging from 1 = *managing well* to 6 = *deep financial trouble* (National Centre for Social Research and Department for Work and Pensions, 2011), with 9.8% reporting some degree of financial struggle. Respondents were from remote (2 %,  $n = 1$ ), rural (9.8%,  $n = 5$ ), suburban (51.0%,  $n = 26$ ), and urban (33.3%,  $n = 17$ ) settings in Ontario (3.9%,  $n = 2$  were missing).

### **Procedure**

As part of a larger project on sport participation for individuals with DD involved in SO, caregivers of athletes involved in SO Ontario filled out an online survey about the sport experiences of their athlete and were asked if they would be interested in participating in an in-person interview with their athlete. Of the caregivers who filled out the initial online survey, 317 (61.4%) agreed to be contacted for an in-person interview. A total of 60 caregivers and their athletes participated in the in-person interview. Data from nine of the athletes were excluded due to inadequate comprehension of the interview questions (See Figure 2). The final sample ( $n = 51$ ) was compared to the original sample ( $n = 516 - 51 = 465$ ) on key demographic characteristics (See Table 1).

There were no significant differences between the final sample and the original sample, except that athletes in the final sample participated in significantly more sports and engaged in sports more often,  $t(57)= 2.98, p = .004$  and  $t(502)= 4.44, p < .001$ , respectively. Informed consent (See Appendix A) and assent (See Appendix B), were obtained from caregivers and athletes, respectively. During the in-person visit, athletes completed the WASI-II, as well as a structured interview assessing physical self-concept, social self-concept, and emotional well-being while caregivers completed a paper-in-pencil survey in a separate room. Clinical Psychology graduate students who had previous training and experience working with individuals with DD conducted the interviews. If they had any concerns about an athlete's level of comprehension, data for that participant were removed. Data were also eliminated if there was a noticeable pattern of acquiescence or unusual responses. Once the athlete interview was finished, caregivers completed the five minute interview using the Five Minute Speech Sample (FMSS) away from their athlete. Each interview lasted approximately 60-120 minutes long. The York University Research Ethics Board approved the study.

## **Measures**

### **Individual Factors.**

**Demographic Information.** Caregivers provided demographic information about themselves (e.g., age and ethnicity) and their athlete (e.g., age, sex).

**Adaptive Behaviour.** Caregivers completed the Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013), which was developed for use with parents of adolescents and adults with ASD and with ID (12 to 48 years of age) and measures an individual's independence in doing a variety of activities in daily living, such as "making

his/her own bed” and “drinking from a cup.” The W-ADL consists of 17-items which are rated on a 3-point scale: “*does not do at all*,” “*does with help*,” “*independent or does on own*.” Higher scores reflect more adaptive behaviour. The W-ADL is strongly correlated with the Vineland Adaptive Behaviour Scale Composite Score and Daily Living subscale ( $r = .78$  and  $r = .78$ , respectively; Maenner et al., 2013), demonstrating strong criterion and construct validity. The internal consistency across samples of individuals with different disabilities ranged from good to excellent (Cronbach’s  $\alpha = .88$  to  $.94$ ; Maenner et al., 2013) and was good for the current study: Cronbach’s  $\alpha = .83$ .

***Body Mass Index (BMI).*** Caregivers provided the weight and height of each athlete. BMI was calculated by dividing the athlete’s weight in kg by his/her squared height ( $\text{kg}/\text{m}^2$ ).

***Intellectual Functioning.*** Two subtests of the WASI-II (Wechsler, 2011), Vocabulary and Matrix reasoning, were administered to athletes to calculate their Full Scale IQ (FSIQ-2). The WASI-II was normed on a sample of 2,300 individuals aged 6 to 90 years. The split-half reliability coefficient for the FSIQ-2 was at least  $.89$  and the test-retest reliability was at least  $.90$  for all age blocks (Irby & Floyd, 2013). Strong support exists for the convergent and discriminant validity of using of the WASI as a brief measure of intelligence (Irby & Floyd, 2013).

***Emotional and Behavioural Problems and Prosocial Behaviour.*** Emotional and behavioural problems were measured using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). The SDQ is a brief 25-item caregiver-report scale composed of five subscales: emotional symptoms, conduct problems, hyperactivity, peer problems, and prosocial behaviour. A total difficulties score was calculated using the Total of all the

subscales except prosocial behaviour. A higher score for all SDQ subscales reflects more emotional and behavioural problems; however, higher scores for the prosocial behaviour subscale indicates more prosocial behaviour. Caregivers rated each item using a three-point scale: “*not true*,” “*somewhat true*”, “*certainly true*.” The SDQ has adequate inter-rater and test-retest reliabilities, and internal consistency (Goodman, 2001). For example, the internal consistency of the SDQ subscales ranged from Cronbach’s  $\alpha = .55$  to  $.80$  in a previous study using a sample of 260 children (6-12 years) with ID (Kaptein, Jansen, Vogels, & Reijneveld, 2008). For the current study, internal consistency was Cronbach’s  $\alpha = .85$  for total difficulties, Cronbach’s  $\alpha = .82$  for emotional symptoms, Cronbach’s  $\alpha = .78$  for conduct problems, Cronbach’s  $\alpha = .78$  for hyperactivity, Cronbach’s  $\alpha = .62$  for peer problems, and Cronbach’s  $\alpha = .82$  for prosocial behaviour. Research suggests that the SDQ is a valid measure of the mental health needs of children and adolescents with ID (Beck et al., 2004; Emerson, 2005).

***SO Participation.*** Caregivers were asked, on average, in the last 12 months, how often their athlete participated in SO sports (“*never, a few times a year, once per month, 2-4 times per month, once a week, or several times a week*”) to give an indication of “SO frequency.” Caregivers were also asked; “In the last 12 months, what SO sports has your child participated in?” Caregivers selected “*Yes*” or “*No*” for 19 different eligible sports to represent “Total Sports”.

#### **Caregiver and Family Factors.**

***Caregiver Mental Health.*** Caregivers completed the Depression Anxiety Stress Scale (DASS-21; Lovibond and Lovibond, 1995) as a measure of caregiver mental health. The DASS-21 consists of 21 items, each of which is rated on a four-point scale

(“never,” “sometimes,” “often,” “almost always,”), and three subscales: depression, anxiety, and stress, with higher scores reflecting more mental health issues. The scale has been shown to have high internal consistency and to discriminate between clinical and community samples (Lovibond and Lovibond, 1995). Internal consistency for the current study was good for depression (Cronbach’s  $\alpha = .89$ ), stress (Cronbach’s  $\alpha = .85$ ), and anxiety (Cronbach’s  $\alpha = .71$ ).

**Family Functioning.** The General Functioning Scale of The McMaster Family Assessment Device (FAD; Epstein et al., 1983) was used to assess family functioning. Caregivers rated 12 items using a four point scale (“strongly agree,” “agree,” “disagree,” “strongly disagree”). Higher scores on the scale correspond with better family functioning. The FAD has adequate test-retest reliability, and convergent and discriminant validity (Friedmann et al., 1997; Wenniger et al., 1993). Herring et al. (2006) used the FAD in a sample of families of children with DD. The internal consistency for the FAD was excellent: Cronbach’s  $\alpha = .90$ .

**Expressed Emotion.** The Five Minute Speech Sample (FMSS; Magana et al., 1986) was used to measure expressed emotion. Caregivers spoke for five minutes about what kind of person their athlete is and how the two of them get along together. These speech samples were recorded, transcribed, and then coded based on the Autism-Specific Five Minute Speech Sample (AFMSS) developed by Benson et al. (2011). The AFMSS coding scheme made adjustments to the FMSS coding scheme to make it more applicable to families of individuals with DD. The AFMSS uses the same coding categories, but adds two additional dimensions: warmth and positive comments. The speech samples were given ratings for the initial statement made by the caregiver (coded positive, neutral,

or negative), the caregiver's relationship with the child (coded positive, neutral, or negative), the level of warmth expressed by the caregiver (coded high moderate, or low), and the emotional over-involvement (EOI) with the child (coded high, moderate, or low). The speech samples were also coded using two frequency counts: the total number of critical comments expressed by the caregiver about the child and the total number of positive comments made by the caregiver about the child. Finally, the speech samples were also given an overall rating of caregiver AFMSS-EE based on the assessment of all six AFMSS components. Initial statement and EOI were removed from analyses due to lack of variability, AFMSS-EE was included because it provides an overall summary rating. Research has demonstrated that this coding scheme for the AFMSS has adequate internal consistency, good to excellent inter-rater and code re-code reliability, and acceptable validity (Beck et al., 2004; Benson et al., 2011). Inter-rater reliability was assessed on 17 randomly selected speech samples by two different raters, and code-recode reliability was assessed using the same 17 randomly selected speech samples coded on two separate occasions approximately one month apart. In the present study, recode-recode reliability for the six EE components assessed by the AFMSS ranged from .70 to 1.00, while inter-rater reliabilities ranged from .73 to 1.00 (See Table 2).

***Financial Management.*** Caregivers were also asked how well they were managing financially, ranging from 1 = *managing well* to 6 = *deep financial trouble*.

#### **Dependent Variables.**

***Indicators of Emotional Well-being.*** Seven indicators of emotional well-being were used based on the research by Emerson and Hatton (2008), which investigated the emotional well-being of individuals with DD. First, we measured athletes' happiness in

three contexts. Athletes were asked, “How do you feel about life at home, school/work, and SO at the moment?” They were asked to choose one of four response options (“*very happy, quite happy, sometimes happy/sometimes unhappy, or mostly unhappy*”) using a visual cue card (See Appendices E, F, & G). Each item was analyzed separately and averaged together to obtain a mean total score (“Well-being Mean”), with higher scores reflecting more happiness.

Athletes’ emotional state was assessed via four questions adapted from Emerson and Hatton (2008) and Pantazis, Gordon, and Levitas (2006): “*All of us feel a bit unhappy or worried at times. Do you ever feel sad or worried?*” If the athlete answered yes, they were then asked, “*Is that a lot or just sometimes?*” This question format was repeated for “left out of things,” “helpless,” and “confident.” Athletes were shown a visual cue card for each question with a picture representing each emotional state. The examiner waited for a verbal or nonverbal yes or no response (See Appendices H, I, J, & K). For feeling “sad/worried,” “left out,” and “helpless,” lower scores reflect more positive well-being, and for feeling “confident,” higher scores reflect more positive emotional well-being (i.e., No = 0; Yes/Sometimes = 1; Yes/A lot = 2). To calculate a mean of the four emotions (“Emotions Mean”), the first three items were reverse coded (i.e., No = 2; Yes/Sometimes = 1; Yes/A lot = 0) and averaged with “confident,” so higher scores reflect more positive emotional well-being.

### **Data Analysis Plan**

Independent-samples *t*-tests were conducted to examine whether females have lower emotional well-being than men. Pearson product-moment correlations were conducted to examine whether age, BMI, IQ, emotional and behaviour problems, SO

Participation, EE, Caregiver mental health, family functioning, and financial management were related to emotional well-being. Multiple linear regressions were used to examine whether including individual and family factors together would predict a significant amount of variance in emotional well-being.

## **Results**

### **Preliminary Analyses**

*Missing Data Analysis.* We examined missing and erroneous data points by conducting frequency and descriptive analyses (See Table 10). Multivariate analyses were conducted listwise so that only individuals with complete data were included.

*Multicollinearity.* Correlations between all independent variables were conducted to assess collinearity. All of the bivariate correlations were less than .90, and, therefore, were acceptable for including in multivariate analysis (Tabachnick & Fidell, 2007). All of the variance inflation factors were less than two.

### **Assumptions For Correlations**

Since many of the variables were not normally distributed, one of the assumptions of Pearson's correlation, the correlations were checked using a non-parametric bootstrap. The same pattern of results emerged.

### **Assumptions For Regressions**

*Independent Errors.* The Durbin-Watson values were between one and three, which suggests that the residuals were uncorrelated.

*Homoscedasticity and Linearity.* The standardized residuals were plotted against the standardized predicted values of the dependent variable based on the model to examine homoscedasticity. These plots indicated that at each level of the predictor

variables, the variance of the residual terms remained constant. They also indicated that the assumption of linearity was met.

***Normally Distributed Errors.*** Histograms and normal P-P plots indicated that the residuals were normally distributed.

***Outliers and Influential Statistics.*** No Cook's distances were above one, so we could assume that none of the cases were exerting undue influence on the models. All of the Mahalanobis distances were less than 11 which suggests that there were no multivariate outliers.

### **Descriptive Analyses**

See Table 11 for the means, standard deviations, and ranges of scores for variables in the second study. The descriptive statistics for the AFMSS are presented in Table 12. The vast majority (98%) of the current sample were classified as low EOI. For the overall rating of AFMSS-EE, 0% of the sample was classified as high EE, 25.5% as moderate (borderline) EE, and 74.5% as low EE. The descriptive statistics for the well-being variables are presented in Table 13.

### **Main Analyses**

Pearson's product-moment correlations were conducted to test the hypotheses that there were significant relationships between individual variables (e.g., age, BMI, IQ, total difficulties, emotional symptoms, conduct problems, hyperactivity, peer problems, prosocial behaviour, total sports, and SO frequency) and family variables (e.g., AFMSS-EE, warmth, relationship, positive comments, critical comments, caregiver stress, caregiver anxiety, caregiver depression, family functioning, and financial management), and indicators of emotional well-being (e.g., well-being at home, well-being at

school/work, well-being at SO, sad/worried, left out, helpless, confident). Independent-means *t*-tests were used to examine sex differences in emotional-well being. There were no significant sex differences for any of the indicators of emotional well-being.

**Happiness.** We found two significant correlations involving well-being at home (See Table 14). Emotional symptoms were significantly negatively related to well-being at home  $r(46) = -.31, p = .03$ , and prosocial behaviour was significantly positively correlated with well-being at home,  $r(46) = .31, p = .03$ . These two variables were entered into a regression predicting well-being at home. The overall model was significant  $F(2, 44) = 3.72, p = .03$ , accounting for 14% of the variance in well-being at home (See Table 16). Emotional symptoms and prosocial behaviour were not significant individual predictors,  $\beta = -.24, p = .11$  and  $\beta = .24, p = .11$ , respectively. Conduct problems were significantly negatively associated with well-being at school/work  $r(45) = -.33, p = .02$ , and family functioning was significantly positively correlated with well-being at SO,  $r(47) = .36, p = .01$  (Table 14).

**Emotional Symptoms.** Emotional symptoms were significantly positively related with feeling sad/worried,  $r(45) = .32, p = .03$ , and prosocial behaviour was positively associated with feeling left out,  $r(45) = .30, p = .04$ . AFMSS-EE and critical comments were positively correlated with feeling helpless,  $r(48) = .32, p = .02$  and  $r(48) = .38, p = .01$ , respectively, while BMI was negatively correlated with feeling helpless,  $r(46) = -.37, p = .01$ . The regression model was significant using these three variables as predictors of feeling helpless,  $F(3, 44) = 7.79, p < .001$ , accounting for 35% of the variance in feeling helpless (See Table 17). BMI, AFMSS-EE, and critical comments were significant predictors of feeling helpless,  $\beta = -.32, p = .02$ ,  $\beta = .34, p = .01$ , and  $\beta = .34, p = .01$ ,

respectively. Family functioning was significantly positively correlated with feeling confident,  $r(45) = .32, p = .03$ , and conduct problems were negatively correlated with mean emotions,  $r(45) = -.34, p = .02$  (See Table 15).

### **Discussion**

The main objective for the current study was to investigate whether individual and family factors were associated with the self-report of emotional well-being for adolescents and young adults with DD involved with SO. Specifically, we hypothesized that individual factors (e.g., age, sex, intellectual functioning, BMI, emotional and behavioural problems, prosocial behaviour, and SO involvement) and family factors (e.g., caregiver mental health, family functioning, EE, and financial management) would be related to emotional well-being. BMI, emotional and behavioural problems, and prosocial behaviour were significantly related to at least one indicator of emotional well-being; however, the other individual factors (e.g., sex, age, intellectual functioning, SO frequency) were not. Three notable family factors (Overall EE, critical comments, and family functioning) were also significantly related to at least one indicator of emotional well-being. Finally, we hypothesized that individual and family factors, together, would significantly predict the emotional well-being of adolescents and young adults with DD, and we found that this was the case for feelings of helplessness.

#### **Indicators of Emotional Well-being**

We examined seven indicators of emotional well-being: Happiness in three contexts (home, school/work, and SO) and four emotional states (sad/worried, left out, helpless, confident). With regard to contexts, results supported the hypothesis that emotional and behavioural problems would be negatively correlated with at least some

indicators of emotional well-being. Athletes with lower parent-reported emotional symptoms and higher prosocial behaviour reported higher emotional well-being at home, accounting for 14% of the variance. Research has highlighted a potential bi-directional relationship between prosocial behaviour and self-esteem, which is theoretically linked to emotional well-being in children and adolescents (Laible, Carlo, & Roesch, 2004). Many have speculated that individuals with high levels of self-esteem are more likely to engage in prosocial behaviour than individuals with low levels of self-esteem (Eisenberg & Fabes, 1998) and that adolescent engagement in prosocial behaviours likely increases self-esteem (Yates & Youniss, 1996). We would also expect that individuals with higher levels of emotional symptoms, based on caregiver report, would self-report lower levels of emotional well-being (Stancliffe et al., 2009).

Conduct problems were significantly negatively correlated with well-being at school/work and with the overall mean of the emotions variables. These findings are consistent with what we would expect given that conduct problems consist of temper tantrums, disobedience, and fighting with peers, all of which would negatively impact emotional well-being at school/work. Moreover, research links conduct problems with peer rejection, depression, and failure to develop academic skills among typically developing individuals (Wolff & Ollendick, 2006); therefore, the effects of conduct problems would likely be heightened in a structured academic setting in comparison to home or SO settings. Family functioning was positively related to athlete reports of well-being at SO in particular, with better family functioning associated with higher well-being at SO. Better family functioning is shown to be related to better adjustment in children (Miller, Ryan, Keitner, Bishop, & Epstein, 2000), so we would expect that

children whose families have higher functioning would have better emotional well-being at SO as well as more generally.

In terms of the emotional states, we found that self-reports of feeling sad/worried were positively correlated with parent reported emotional symptoms. This finding is consistent with what we hypothesized and with previous literature (e.g., Stancliffe et al., 2009), indicating an important connection between parent and self-reported emotional well-being. Feeling left out was positively associated with higher levels of prosocial behaviour, which is opposite to what we hypothesized. Athletes who have higher levels of prosocial behaviour may have higher expectations for social relationships and subjectively experience loneliness more acutely, which is consistent with the definition of loneliness proposed by Peplau and Perlman (1982). Self-reported helplessness was positively related with the overall level of parent EE and the number of critical comments expressed by parents, and negatively associated with BMI, and all emerged as unique predictors. Higher levels of EE are consistently shown to be associated with behaviour problems and psychopathology in the general DD population, fitting with our results (e.g., Baker et al., 2011; Greenberg et al., 2006; Hastings et al., 2006). The current study found that BMI was negatively correlated with feeling helpless, with individuals with higher BMI reporting lower levels of helplessness, which is in contrast to community based prospective studies of typically developing adolescents that have shown that higher BMI is associated with more symptoms of depression including feelings of helplessness (Goodman & Whitaker, 2002; Pine, et al., 2001). Individuals with DD may have different assumptions, expectations, and perceptions of their body compared to typically developing individuals (Salaun, Reynes, & Berthouze-Aranda, 2014). Moreover, having a

high BMI may be a particular advantage for athletic individuals with DD compared to non-athletic individuals with DD, if the higher BMI reflects higher muscle mass. More research is needed to examine body image among athletes with DD to explore the relationship between BMI and emotional well-being. Finally, feeling confident was significantly positively correlated with family functioning, which was consistent with our hypotheses and supports the body of research suggesting that family functioning plays an important role in child outcomes. The current study adds to the existing body of research because we used self-reports of well-being rather than parent proxy report.

The other individual factors (e.g., age, sex, level of functioning, involvement in SO) were not significantly associated with any indicators of emotional well-being, and there are several possible reasons why. The main reason being that previous research typically relied on proxy measures of psychopathology rather than self-report (e.g., Hastings et al., 2005). With regards to the lack of significant findings for involvement in SO, our two involvement variables (diversity and frequency of involvement) may be less important for this population. Participation alone (compared to no participation) may be the key factor of importance, as was the case in Gibbons and Bushakra (1989). The lack of significant findings in the current study highlights the need to examine other individual predictors when investigating emotional well-being using self-report. For example, level of social skills may be an important variable to consider when investigating the self-reported emotional well-being of individuals with DD (Emerson & Hatton, 2008). Another reason why the current study may not have found significant effects of SO participants is that the sample involved youth and young adults between the ages of 12 and 22. Emerson and Hatton (2008) did find a relationship between age and emotional

well-being among persons with ID, but their work was primarily focused on adults with all of their participants at least 17 years of age. There may be different indicators of well-being for youth with DD compared to adults with DD. The current study also differed from previous literature in that it consisted of a specific subgroup of individuals with DD who are involved in SO. The predictors of emotional well-being for this subgroup of individuals appears to be different compared to other individuals with DD who are not involved with SO.

None of the caregiver mental health variables (e.g., caregiver stress, caregiver anxiety, caregiver depression) were related to any of the indicators of athlete emotional well-being, nor was financial management. There may have been insufficient variability in caregiver mental health and financial management to detect an association. The majority of caregivers fell within the normal range for caregiver stress, caregiver anxiety, and caregiver depression, and only 9.8% of caregivers reported some degree of financial struggle, so these families may not be representative of the full range of concerns experienced by parents of individuals with DD including poverty (Emerson, 2003b) and mental health problems (Olsson & Hwang, 2001).

### **Limitations**

There were several limitations to the current study. One limitation of the current study was that the sample is not representative of all individuals with DD, nor is it representative of all families involved with SO. At the same time, apart from the amount of SO participation, our sample did not significantly differ from the larger sample of SO participants (See Table 1). Focusing on this specific subgroup of individuals was also a strength of the study because it allowed for a more in-depth analysis of this particular

subgroup of individuals with DD involved with SO. This study was also limited because the analyses were correlational, so we could not determine causal relationships among the variables, and the sample was small, which impacted the statistical power. In addition to sport frequency and the total number of sports, other variables related to sport involvement such as number of medals received or quality of sport involvement are worth investigating. These sport variables might also be important correlates of emotional well-being. Another limitation is the validity of measuring the internal states of individuals with DD; however there is a strong rationale for doing so and the current study employed the same measures as previous studies to ensure reliability and validity (e.g., Emerson & Hatton, 2008; Glidden et al., 2011).

### **Future Studies**

Few studies have examined the emotional well-being of individuals with DD using self-report, and further research is needed to understand the emotional well-being of individuals with DD involved in SO, more specifically. Participation in SO has benefits for individuals with DD in terms of physical fitness (Balic, Mateos, & Blasco, 2000) self-concept (Weiss et al., 2003), and emotional well-being (Glidden et al., 2011) and it is valuable to investigate how sport involvement (compared to non-involvement), along with individual and family variables external to SO are related to self-reported emotional well-being. A promising avenue of research is to longitudinally examine the factors that influence the emotional well-being of individuals with DD. Research examining the effectiveness of Cognitive Behavioural Therapy interventions with individuals with DD often employs the use of thought records and mood diaries (e.g., Hassiotis et al., 2013), and research could use these methods to track the mood of

individuals with DD over time to examine the predictors of emotional well-being. Taking into account the current study's results linking emotional well-being with emotional and behavioural problems and parent EE, longitudinal research would help to further our understanding of these findings.

### **Clinical Application**

The results of the current study have important implications for families and clinicians working with individuals with DD involved in SO, and it is important that clinicians target emotional and behavioural problems when they are working with youth with DD and their families using evidence-based behavioural (Grey & Hastings, 2005) and cognitive behavioural interventions (Dagnan & Jahoda, 2006). The connection between family expressed emotion and emotional well-being also suggests that working with families can impact the emotional well-being of children. While very little research has examined the effectiveness of family therapy for individuals with DD (Brown, Duff, Karatzias, & Horsburg, 2011), there are promising avenues for addressing emotional and behavioural challenges for parents and children with DD using mindfulness parenting (Sing et al., 2007), Acceptance and Commitment Therapy (Blackledge & Hayes, 2006), and Soles of the Feet, a mindfulness-based intervention (Sing et al., 2011).

### **Conclusion**

The current study was the first to examine individual and family factors and their relationship to emotional well-being for individuals with DD involved in SO, adding to the limited research that has examined emotional well-being of individuals with DD using self-report. The results of the study highlight the importance of individual factors (e.g., emotional and behavioural problems) and family factors (e.g., overall level of

parent EE and critical comments) for the emotional well-being of individuals with DD involved in SO, providing a foundation for future research. To further understand and promote emotional well-being for individuals with DD, an ongoing challenge is to conduct studies that examine emotional well-being in individuals with DD across the lifespan, using cross-sectional and longitudinal techniques.

### **General Discussion**

The findings from the two studies highlight key themes for adolescents and young adults with DD involved in SO. Across both studies, emotional and behavioural problems were important individual factors, correlated with social self-concept and emotional well-being. Other important individual factors related to self-concept included age, BMI, and SO participation in the first study, whereas family factors (i.e., family functioning, AFMSS-EE, and critical comments) were associated with emotional well-being in the second study. These findings draw attention to the need to broadly examine individual and family correlates of physical and social self-concept and emotional well-being for individuals with DD. Despite consistent themes across both studies, different patterns and predictors emerged for self-concept compared to emotional well-being. These results point to the need to identify the unique individual and family predictors for the internal experiences of individuals with DD. Clearly, certain variables are important across broad dimensions of their internal experience, while others are unique to specific aspects of their experience. Clinically, these similarities and differences are important so that interventions are targeted to the needs of clients and their families.

The findings of the two studies have important clinical implications with regard to emotional and behavioural problems. Individuals with DD experience high rates of

problem behaviours and are prone to associated mental health problems (Koritsas & Iacono, 2012; Lundqvist, 2013; Stancliffe et al., 2009), so interventions are necessary to interrupt the pathways that might lead to lower levels of social self-concept and emotional well-being (e.g., behavioural management interventions, parent training programs (Einfeld, Tonge, & Clarke, 2013), and cognitive behaviour therapy (Brown et al., 2011)). The findings also suggest that families of individuals with DD who are at risk for low emotional well-being are important targets for interventions such as mindfulness parenting (Sing et al., 2007), and Acceptance and Commitment Therapy (Blackledge & Hayes, 2006). Self-determined motivation is an important potential mechanism of change when it comes to improving physical and social self-concept and emotional well-being including. Defined as performing an activity because it is important to the individual and/or because of the inherent pleasure in the activity (Farrell et al., 2004), self-determined motivation is associated with positive outcomes such as persistence and performance (Deci, Vallerand, Pelletier, & Ryan, 1991) and may be a mediator of, and therefore an important intervention target for, improving self-concept and emotional well-being for individuals with DD involved in Special Olympics.

The only way to access the internal, subjective experience of individuals with DD is through self-report (Cummins, 2002). While there are challenges and limitations to using self-report with this population, there is a strong body of research confirming the validity and reliability of doing so (e.g., Emerson, 2005). Future research should continue to demonstrate the psychometric properties of self-report measures for individuals with intellectual and adaptive limitations, and researchers should continue to work towards distinguishing between individuals who can respond reliably and validly from those who

cannot. Establishing practice guidelines, such as reporting the cognitive and language skills of participants (Emerson, Felce, & Stancliffe, 2013) along with the psychometric properties of instruments, will help to determine which scales are appropriate for individuals with DD.

Longitudinal studies will help to establish the direction of the relationships between individual/family factors and outcome variables. A larger sample will allow for researchers to examine the mother-child relationship and the father-child relationship and other participant characteristics (such as DD diagnosis) separately. Additionally, clinical studies will be useful to investigate whether individual and/or family interventions impact self-concept and emotional well-being. An exciting avenue of future research will be to use multiple research methods including behavioural and observational coding to explore the self-report of self-concept and emotional well-being of individuals with DD. Finally, more robust ways of measuring the internal states of this population are needed across the lifespan, especially for individuals with more severe impairments in communication for whom alternative forms will be necessary.

Despite the large body of research on self-concept and emotional well-being for individuals in the general population, few investigations have examined these constructs from the point of view of individuals with DD. The current findings highlight the importance of understanding the inner experience of adolescents and young adults with DD, whose perspectives, while valid, are too often overlooked. Only when research methodology expands to include their voices will we be able identify the predictors, mediators, and pathways for social and physical self-concept and emotional well-being.

Exploring the strengths and limitations of self-report data for participants who differ in cognitive and linguistic abilities will ultimately lead to improvements in quality of life for individuals with DD.

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Table 1

*Final Sample Compared to the Original Sample on Key Variables*

Variables		Original Sample		Final Sample		Test Statistic
		% (N)	Mean (SD)	% (N)	Mean (SD)	
Child Age			17.20 (3.06)		17.02 (3.03)	$t(512) = -.40, p = .69$
Caregiver Age			48.91 (6.06)		49.80 (6.95)	$t(484) = .97, p = .33$
Adaptive Behaviour			20.88 (6.41)		21.98 (5.02)	$t(422) = 1.15, p = .25$
Total Sports			2.22 (1.41)		2.96 (1.69)	$t(57) = 2.98, p = .004$
SO Frequency			1.85 (.81)		2.38 (.73)	$t(502) = 4.44, p < .001$
Total Difficulties			13.23 (6.38)		12.94 (6.49)	$t(398) = -.30, p = .77$
Family Functioning			3.26 (.49)		3.26 (.44)	$t(395) = .04, p = .97$
Child Sex	Male	66.0 (307)		54.0 (27)		$\chi^2 = 2.86, p = .09$
Caregiver Sex	Male	15.7 (72)		14 (7)		$\chi^2 = .10, p = .76$
Caregiver Relationship	Mother	81.3 (373)		80.0 (40)		$\chi^2 = 1.88, p = .76$
	Father	13.3 (61)		12.0 (6)		
	Grandparent	1.1 (5)		2.0 (1)		
	Sibling	1.1 (5)		0 (0)		
	Other	3.3 (15)		6.0 (3)		
Finances	We manage very well	12.0 (45)		10.4 (5)		$\chi^2 = 2.47, p = .78$
	We manage quite well	28.1 (105)		35.4 (17)		
	We get by alright	42.8 (160)		43.8 (21)		
	We don't manage very well	3.2 (12)		2.1 (1)		
	We have some financial difficulties	12.0 (45)		8.3 (4)		
	We are in deep financial trouble	1.9 (7)		0 (0)		
	Health	Very Poor	0.5 (2)		0 (0)	
	Poor	9.2 (34)		4.0 (2)		
	Good	68.5 (254)		70.0 (35)		
	Excellent	21.8		26.0		

Caregiver Education	No certificate	(81) 2.3 (9)	(13) 4.0 (2)	$\chi^2 = 7.10, p = .21$
	High school certificate or equivalent	19.3 (74)	12.0 (6)	
	Apprenticeship or trades certificate or diploma, College, CEGEP	38.0 (146)	28.0 (14)	
	University certificate, diploma, or degree (undergraduate level)	29.4 (113)	46.0 (23)	
	University certificate, diploma, or degree at the Master's or PhD (graduate) level	10.4 (40)	10.0 (5)	
	Not sure	0.5 (2)	0 (0)	
Other Caregiver Education	No certificate	8.2 (31)	2.0 (1)	$\chi^2 = 3.09, p = .69$
	High school certificate or equivalent	20.8 (79)	24.5 (12)	
	Apprenticeship or trades certificate or diploma, College, CEGEP	36.9 (140)	34.7 (17)	
	University certificate, diploma, or degree (undergraduate level)	21.40 (81)	22.4 (11)	
	University certificate, diploma, or degree at the Master's or PhD (graduate) level	10.6 (40)	14.3 (7)	
	Not sure	2.1 (8)	2.0 (1)	
Single person household	Yes	17.40 (75)	21.7 (10)	$\chi^2 = .53, p = .47$

Table 2

*Reliability of AFMSS Components as Measured by the AFMSS (n =17)*

AFMSS Components	Inter-rater ( <i>ICC</i> )	Code-recode ( <i>ρ</i> )
Initial Statement	1.00	.87
Warmth	.73	.85
Relationship	.94	1.00
Emotional Over-Involvement	#	#
Critical comments	.78	.70
Positive comments	.92	.97
AFMSS-EE	.81	.84

## = *ICC* and *ρ* cannot be computed due to perfect inter-rater and code-recode agreement and no variability across participants. All other correlations are significant at the  $p < .05$  level.

*ICC*= Intraclass correlation coefficient

*ρ* = Spearman's rank correlation coefficient

Table 3

*Summary of Missing Data Study One*

Variable	<i>N</i>	% Missing	
Independent Variables	Child Sex	0	
	Child Age	0	
	BMI	3.9	
	WASI Full Scale IQ	0	
	Total Difficulties	9.8	
	Emotional Symptoms	5.9	
	Peer Problems	3.9	
	Hyperactivity	5.9	
	Conduct Problems	5.9	
	Prosocial Behaviour	5.9	
	Total Sports	2.0	
	SO Frequency	2.0	
	AFMSS-EE	0	
	Warmth	0	
	Relationship	0	
	Positive Comments	0	
	Critical Comments	0	
	Caregiver Stress	3.9	
	Caregiver Anxiety	5.9	
	Caregiver Depression	3.9	
	Family Functioning	3.9	
	Financial Management	3.9	
	Dependent Variables	Social Self-Concept	2.0
		PSI: Overall Mean	3.9
		PSI: Physical Self-Worth	2.0
		PSI: Physical Condition	2.0
PSI: Sport Competence		3.9	
PSI: Physical Condition		2.0	

Table 4

*Variable Means (SD) and Ranges for Study One*

Variable	<i>M (SD)</i>	Range	
		Potential	Actual
Total Difficulties	12.37 (6.67)	0-40	1-30
Emotional Symptoms	2.94 (2.72)	0-10	0-10
Peer Problems	3.67 (2.23)	0-10	0-9
Hyperactivity	4.52 (2.44)	0-10	1-10
Conduct Problems	1.31 (1.86)	0-10	0-8
Prosocial Behaviour	7.35 (2.23)	0-10	2-10
Total Sports	2.96 (1.69)	0-19	1-7
Sport Frequency	2.38 (.73)	1-3	1-3
Caregiver Stress	4.57 (3.62)	0-21	0-16
Caregiver Anxiety	.94 (1.58)	0-21	0-9
Caregiver Depression	2.14 (3.12)	0-21	0-12
Family Functioning	3.34 (.46)	1-4	2-4
Social Self-Concept	3.28 (.99)	0-5	1.14-5
PSI: Overall Mean	3.47 (.92)	0-5	.92-5
PSI: Physical Self-Worth	3.99 (1.23)	0-5	0-5
PSI: Physical Condition	2.66 (1.71)	0-5	0-5
PSI: Sport Competence	3.56 (1.39)	0-5	0-5
PSI: Physical Attractiveness	3.21 (1.50)	0-5	0-5

Table 5

*Descriptive Statistics for AFMSS Components (N=51)*

AFMSS Variable	<i>n</i> (%)
Initial statement	
Positive	19 (37.3)
Neutral	32 (62.7)
Negative	0 (0)
Warmth	
High	9 (17.6)
Moderate	30 (58.8)
Low	12 (23.5)
Relationship	
Positive	23 (45.1)
Neutral	26 (51)
Negative	2 (3.9)
Emotional over-involvement	
High	0 (0)
Moderate	1 (2.0)
Low	50 (98.0)
Number of critical comments	
Mean (SD)	.20 (.49)
Range	0-2
Number of positive comments	
Mean (SD)	4.47 (3.55)
Range	0-15
AFMSS-EE	
High	0 (0)
Moderate (borderline)	13 (25.5)
Low	38 (74.5)

Table 6

*Correlations Between Predictor Variables and Social Self-Concept*

		Social Self-Concept
Individual Factors	Child Age	.29*
	BMI	.18
	Total Difficulties	-.31*
	Emotional Symptoms	-.03
	Peer Problems	-.29*
	Hyperactivity	-.26
	Conduct Problems	-.20
	Total Sports	.32*
	SO Frequency	.36*
Family Factors	AFMSS-EE	.04
	Warmth	-.08
	Relationship	.08
	Positive Comments	-.02
	Critical Comments	-.07
	Caregiver Stress	.15
	Caregiver Anxiety	-.12
	Caregiver Depression	.05
Family Functioning	.07	

+  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$

Table 7

*Variables Predicting Social Self-Concept (N = 44)*

Variable	<i>B</i>	<i>SE B</i>	$\beta$	<i>p</i>
Constant	2.07	.87		.02
Child Age	.06	.05	.18	.23
Total Difficulties	-.04	.02	-.28	.06
SO Frequency	.33	.19	.25	<.10
$R^2$		.22		
F for Model		3.65		.02

Table 8

*Correlations between Predictor Variables and Physical Self-Concept for Study One*

	Variable	PSI: Overall Mean	PSI: Physical Self- Worth	PSI: Physical Condition	PSI: Sport Competence	PSI: Physical Attract- iveness
Individual Factors	Child Age	-.18	.04	-.43**	-.10	-.02
	BMI	-.19	.06	-.47**	-.04	-.22
	Total Difficulties	-.06	.08	-.15	-.06	.07
	Emotional Symptoms	-.08	.14	-.24	-.12	.05
	Peer Problems	-.16	.01	-.23	-.17	.05
	Hyperactivity	.15	.01	.14	.11	.13
	Conduct Problems	.00	.14	.02	.05	.01
	Total Sports	.09	.21	.20	.16	-.22
	SO Frequency	-.03	.20	.03	-.03	-.09
Family Factors	AFMSS-EE	-.01	-.05	-.07	-.03	.02
	Warmth	-.17	-.08	-.06	-.14	-.10
	Relationship	.06	.01	.14	.23	-.01
	Positive Comments	-.12	-.03	.04	.00	-.12
	Critical Comments	.02	.02	.13	.07	.02
	Caregiver Stress	.05	-.02	.12	-.02	-.07
	Caregiver Anxiety	.13	.14	.06	.12	-.05
	Caregiver Depression	.03	-.13	.14	-.10	.05
Family Functioning	-.08	.08	-.09	.04	.05	

+  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$

Table 9

*Variables Predicting Physical Self-Concept: Physical Condition (N = 48)*

Variable	<i>B</i>	<i>SE B</i>	$\beta$	<i>p</i>
Constant	7.69	1.24		<.001
Child Age	-.16	.08	-.30	.05
BMI	-.10	.05	-.31	.04
$R^2$		.29		
F for Model		8.98		.001

Table 10

*Summary of Missing Data Study Two*

Variable	<i>N</i>	% Missing
Dependent Variables		
Well-being at Home	51	0
Well-being at School/Work	50	2
Well-being at SO	51	0
Well-being Mean	51	0
Confident	49	3.9
Sad/worried	49	3.9
Left out	50	2
Helpless	50	2
Emotions Mean	50	2

Table 11

*Variable Means (SD) and Ranges for Study Two*

Variable	M (SD)	Range	
		Potential	Actual
Well-being at Home	3.50 (.81)	1-4	1-4
Well-being at School	3.22 (.86)	1-4	1-4
Well-being at SO	3.67 (.65)	1-4	1-4
Well-being Mean	3.47 (.58)	1-4	1.67-4
Confident	1.29 (.65)	0-2	0-2
Sad/Worried	.67 (.55)	0-2	0-2
Left out	.54 (.65)	0-2	0-2
Helpless	.48 (.68)	0-2	0-2
Emotions Mean	1.40 (.36)	0-2	0.75-2

Table 12

*Descriptive Statistics for AFMSS Components (N=51)*

AFMSS Variable	<i>n</i> (%)
Initial statement	
Positive	19 (37.3)
Neutral	32 (62.7)
Negative	0 (0)
Warmth	
High	9 (17.6)
Moderate	30 (58.8)
Low	12 (23.5)
Relationship	
Positive	23 (45.1)
Neutral	26 (51)
Negative	2 (3.9)
Emotional over-involvement	
High	0 (0)
Moderate	1 (2.0)
Low	50 (98.0)
Number of critical comments	
Mean (SD)	.20 (.49)
Range	0-2
Number of positive comments	
Mean (SD)	4.47 (3.55)
Range	0-15
AFMSS-EE	
High	0 (0)
Moderate (borderline)	13 (25.5)
Low	38 (74.5)

Table 13

*Descriptive Statistics for Emotional Well-Being Items*

Well-being Variables	<i>n</i> (%)
Well-being at Home	
Very happy	35 (68.6)
Quite happy	8 (15.7)
Sometimes happy	7 (13.7)
Mostly unhappy	1 (2)
Well-being at School/Work	
Very happy	24 (47.1)
Quite happy	14 (27.5)
Sometimes happy	11 (21.6)
Mostly unhappy	1 (2)
Missing	1 (2)
Well-being at SO	
Very happy	38 (74.5)
Quite happy	10 (19.6)
Sometimes happy	2 (3.9)
Mostly unhappy	1 (2)
Feels Sad or Worried	
A lot	2 (3.9)
Sometimes	29 (56.9)
Never	18 (35.3)
Missing	2 (3.9)
Feels Left Out	
A lot	4 (7.8)
Sometimes	19 (37.3)
Never	27 (52.9)
Missing	1 (2)
Feels Helpless	
A lot	5 (9.8)
Sometimes	14 (27.5)
Never	31 (60.8)
Missing	1 (2)
Feels Confident	
A lot	19 (37.3)
Sometimes	25 (49)
Never	5 (9.8)
Missing	2 (3.9)

Table 14

*Correlations Between Predictor Variables and Well-Being Items*

	Variable	Well-being at home	Well-being at school/work	Well-being at Special Olympics	Well-being Mean	
Individual Factors	Child Age	.07	.09	-.03	.07	
	BMI	.01	.09	.02	.06	
	WASI Full Scale IQ	-.10	-.09	-.13	-.15	
	Total Difficulties	-.28+	-.26	.03	-.25	
	Emotional Symptoms	-.31*	-.17	-.01	-.23	
	Peer Problems	-.13	-.11	-.06	-.15	
	Hyperactivity	-.10	-.05	.08	-.04	
	Conduct Problems	-.23	-.33*	.11	-.24	
	Prosocial Behaviour	.31*	.01	.02	.16	
	Total Sports	.13	-.09	.15	.07	
	SO Frequency	-.02	-.13	.02	-.07	
	Family Factors	AFMSS-EE	-.04	-.09	-.12	-.09
		Warmth	.10	.13	.10	.13
Relationship		.01	-.05	.10	.01	
Positive Comments		.06	.12	.16	.14	
Critical Comments		-.11	.09	.08	.02	
Caregiver Stress		.14	.28+	.13	.26+	
Caregiver Anxiety		-.04	-.01	.10	.04	
Caregiver Depression		.05	.26+	-.08	.12	
Family Functioning		.23	-.12	.36*	.18	
Financial Management	.09	.14	-.05	.10		

+  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$

Table 15

*Correlations Between Predictor Variables and Emotion Items*

	Variable	Sad/ worried	Left out	Helpless	Confident	Emotions Mean	
Individual Factors	Child Age	-.05	-.16	-.21	.05	.19	
	BMI	.12	-.01	-.37*	-.08	.12	
	WASI Full Scale IQ	-.13	-.08	-.08	.21	.22	
	Total Difficulties	.24	.10	.08	-.18	-.29	
	Emotional Symptoms	.32*	.07	-.05	-.13	-.22	
	Peer Problems	.01	.08	.13	-.09	-.15	
	Hyperactivity	-.01	-.08	-.01	-.09	-.03	
	Conduct Problems	.28	.19	.10	-.22	-.34*	
	Prosocial Behaviour	.06	.30*	.23	.17	-.19	
	Total Sports	.22	.01	-.02	.23	.01	
	SO Frequency	.14	-.09	-.03	-.01	-.02	
	Family Factors	AFMSS-EE	.02	.07	.32*	-.05	-.21
		Warmth	.01	.08	-.21	.04	.08
		Relationship	.16	-.06	-.21	-.02	.01
Positive Comments		.15	-.02	-.11	.14	.08	
Critical Comments		.02	-.03	.38**	.01	-.17	
Caregiver Stress		-.12	-.07	-.12	.17	.17	
Caregiver Anxiety		.12	.14	-.05	-.12	-.15	
Caregiver Depression		-.17	.01	.16	.06	.03	
Family Functioning		.13	.25	.02	.32*	-.03	
Financial Management		-.01	-.11	-.02	-.09	.04	

+  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$

Table 16

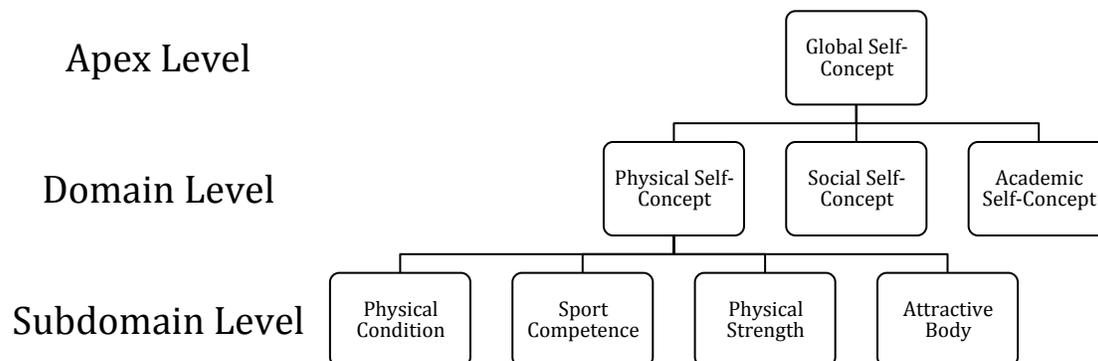
*Variables Predicting Well-Being at Home (N = 47)*

Variable	<i>B</i>	<i>SE B</i>	$\beta$	<i>p</i>
Constant	3.03	.46		<.001
Emotional Symptoms	-.07	.04	-.24	.11
Prosocial Behaviour	.09	.05	.24	.11
$R^2$		.14		
F for Model		3.72		.03

Table 17

*Variables Predicting Feeling Helpless (N = 48)*

Variable	<i>B</i>	<i>SE B</i>	$\beta$	<i>p</i>
Constant	.62	.43		.16
BMI	-.04	.02	-.32	.02
AFMSS-EE	.51	.19	.34	.01
Critical Comments	.46	.17	.34	.01
$R^2$		.35		
F for model		7.79		<.001



*Figure 1.* The hierarchical model of self-concept (adapted from Fortes, Ninot, & Delignières, 2004).

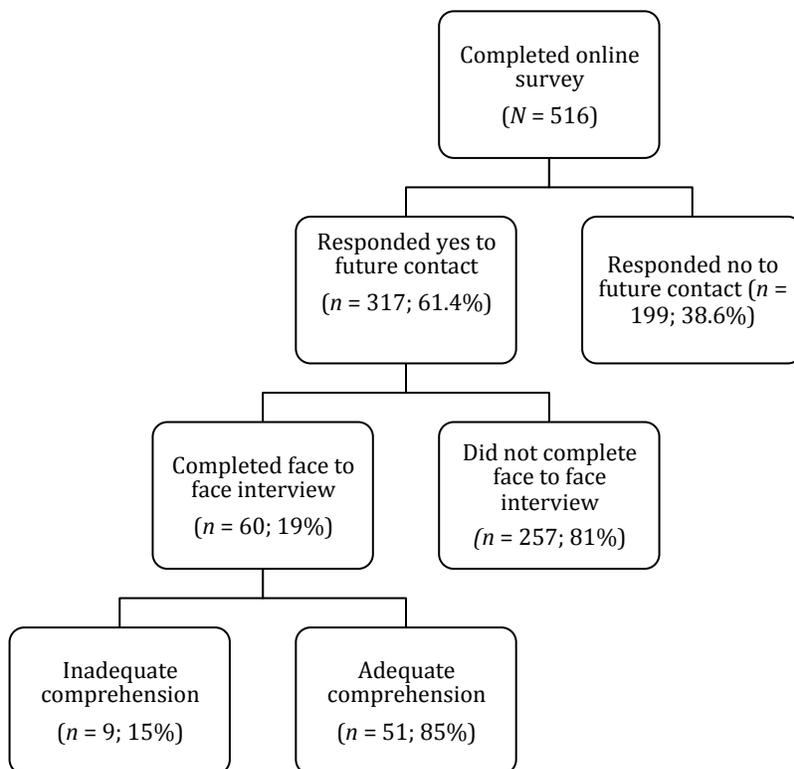


Figure 2. The flow of participants.

## Appendices

### Appendix A: Consent

#### RESEARCH CONSENT (PARENT)

**INTRODUCTION:** As part of the Sport Participation in Youth with Intellectual Disabilities (SPYID Project) where we are learning about athletes in Special Olympics, we would like to interview you briefly and your son or daughter who is in Special Olympics. Your part takes a maximum of 5 minutes, and your child's part takes at most 30 minutes.

This study is overseen by Dr. Jonathan Weiss, C.Psych., principal investigator. Jonathan can be reached if you should have further questions about this study. This study has been approved by the agency's research and ethics committee and the York University Human Participants Review ('Ethics') Sub-Committee. If you have any questions/concerns about this research, you can contact the Senior Manager & Policy Advisor, Office of Research Ethics at York University, 309 York Lanes.

**TOPIC:** "Sport Participation for Youth with Intellectual Disabilities: SPY-ID"

**PARTICIPATION:** Your participation, and your child's participation in this study would involve:

For your child:

- Answering a brief set of questions about how they problem solving
- Answering questions about how they feel about being in sports, being with peers, and in Special Olympics. These are all done with very structures questions that will be read to your child by the research assistant. They can either say or point to the response that they would like to express.

For you:

- Answering one question asking you to describe your child, for 5 minutes. We will audio-tape this recording.

There are very few risks to this research. Your child may not understand all of the questions we ask them. If they appear

uncomfortable or ask to stop, we will stop right away. The questions are worded in a positive way.

**You or your child may withdraw from this study at any time**, even after having signed this form. You are free to refuse to answer any questions. If you withdraw from the study, all information collected will be immediately destroyed where possible.

**CONFIDENTIALITY:** Any information that is collected will be kept **confidential** to the full extent of the law, in a secure location, for 10 years. Your name will be removed from any data collected from you. Instead, a number will be assigned and only the principal investigator and his assistant(s) will have access to the list of names of participants. The information you share will be combined with other participants' information, and **you or your child will never be identified** in any way if/when the results of this study are published.

**Please indicate below your agreement to participate in this research.**

Parent Name:

Phone  
Number:

I UNDERSTAND THE PURPOSE AND THE TERMS OF THE PROJECT  
DESCRIBED ABOVE AND AGREE TO PARTICIPATE AND HAVE MY CHILD  
PARTICIPATE IN THIS RESEARCH STUDY:

“Sport Participation for Youth with Intellectual Disabilities: SPY-ID”

Parent / Guardian Signature

Print Name

Date

Signature of Witness

Print Name

Date

#### CONSENT AND RELEASE: AUDIO, VIDEO AND PHOTOGRAPHY

Research Project: “Sport Participation for youth with intellectual disabilities: SPYID”

#### **Parent Consent for Audiovisual Recording:**

In addition to consenting to participate in this research project, and to having your child participate, we would like to ask your permission to make a recording of one question that we have for you (audio only).

The specific events to be recorded is a 5 minute segment where we ask you to talk about your child.

The date(s) upon which the recording will occur is/are: Today.

The recording may identify your child by name if you give it. If you choose not to consent, we won't audiotape you or ask you about your child.

The recording is being prepared for the following purposes: (1) Research analysis of how parents talk about their children with intellectual disabilities. You don't have to talk about Special Olympics.

The recording may not be used for any other purpose. This includes but is not limited to making copies of the videotape or distributing the videotape to others.

The recording may only be viewed by the researchers involved in this study.

The recording will be kept in a locked cabinet at York University, and kept for 10 years, after which time all copies will be destroyed.

If you want to withdraw your consent to the collection, use or disclosure of this recording, you can notify Dr. Jonathan Weiss, Principal Investigator. You can withdraw your consent at any time. If you have any questions about this recording, you can ask Dr. Jonathan Weiss. If you have any questions/concerns about this research, you can contact the Senior Manager & Policy Advisor, Office of Research Ethics at York University, 309 York Lanes.

I understand that:

1. My agreement or refusal to participate will in no way influence my care and treatment at York University or elsewhere;
2. This recording cannot be used by York University for any other purpose or shown to any other audience than is listed on this form;
3. Staff at York University do not have to notify me when they use this recording for the purposes listed on this form; and
4. I do not have a right to approve the recording before it is used or disclosed for the purposes listed on this form.

**I UNDERSTAND THE PURPOSE AND THE TERMS OF THE PROJECT DESCRIBED ABOVE AND AGREE TO BE AUDIOTAPED.**

Parent/Guardian: \_\_\_\_\_  
(Signature)

Date: \_\_\_\_\_  
(dd/mm/yyyy)

Witness: \_\_\_\_\_  
(Signature)

\_\_\_\_\_  
(Print Name)

*(To be completed and signed off by York University Research Staff)*

I have explained the content of the form and the implications of consent to this client/patient and he/she appeared to understand the information about the decision and the nature and consequences of giving or refusing consent.

I believe that the client/patient's consent is freely given and that he/she is capable to give consent.

\_\_\_\_\_  
*(Signature)*

\_\_\_\_\_  
*(Print Name and Credentials)*

Date: \_\_\_\_\_  
*(dd/mm/yyyy)*

## Appendix B: Assent

**Name of Principle Investigator:** Dr. Jonathan Weiss

**This Informed Assent Form has two parts:**

- Information Sheet (gives you information about the study)
- Certificate of Assent (this is where you sign if you agree to participate)

**Part I: Information Sheet**

Introduction

- My name is \_\_\_\_\_ and my job is to research about Special Olympics
- I am going to give you information and invite you to be a part of this project about you and Special Olympics
- We have discussed this project with your parent and they know that we are also asking you for your agreement. If you are going to participate in this project your parent also has to agree.
- There may be some words that you don't understand or things that you want me to explain more about because you are interested or concerned. Please ask me anytime and I will take time to explain.

**Purpose: Why are you doing this research?**

We want to learn about how you feel about being in Special Olympics.

**Participation is voluntary: Do I have to do this?**

You don't have to be in this project if you don't want to be. It's up to you. If you decide not to be in the project, it's okay and nothing changes. Everything stays the same as before.

*I have checked with the youth and they understand that participation is voluntary*  
 \_\_\_\_\_ *(initial)*

**Procedures: What is going to happen?**

- I am going to ask you questions now to learn about you and how you feel. The questions have pictures on them. You can just try your best.

*I have checked with the child and they understand the procedures* \_\_\_\_\_ *(initial)*

**Risks: Is this bad or dangerous for me?**

There isn't anything dangerous for you.

*I have checked with the child and they understand the risks and discomforts*  
 \_\_\_\_\_ *(initial)*

**Benefits: Is there anything good that happens to me?**

Many athletes who participate feel good about sharing about their feelings and Special Olympics.

*I have checked with the child and they understand the benefits\_\_\_\_\_ (initial)*

**Confidentiality: Is everybody going to know about this?**

- We won't tell anyone else what you tell us here, except
  - if you tell us that there is an adult who is hurting you or
  - if you tell us that you are going to seriously hurt yourself or someone else

**Right to Refuse or Withdraw: Can I choose not to be in the research? Can I change my mind?**

- Remember, you don't have to answer any questions that you do not want to answer.
- You can stop at any time

**Who to Contact: Who can I talk to or ask questions to?**

If you have any questions you can ask your parent or the doctor who is leading the project (Dr. Jonathan Weiss). You can ask me questions now or later. If you want to talk to someone else that you know like your teacher or doctor, that's okay too.

**If you choose to be part of this research I will also give you a copy of this paper to keep for yourself. You can ask your parents to look after it if you want.**

---

**PART 2: Certificate of Assent**

- **I know that I can choose to be in the research study or choose not to be in the research study. I know that I can stop whenever I want.**
- **I have read this information (or had the information read to me) and I understand it.**
- **I have had my questions answered and know that I can ask questions later if I have them.**
- **I understand any changes to this will be discussed with me.**
- **I agree to take part in the research.**

*OR*

- **I do not wish to take part in the research and I have not signed the assent below. \_\_\_\_\_ (initialed)**

Only if child assents:

Print name of child \_\_\_\_\_

Signature of child: \_\_\_\_\_

Date: \_\_\_\_\_  
day/month/year

I have accurately read or witnessed the accurate reading of the assent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given assent freely.

Print name of researcher \_\_\_\_\_

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

Date \_\_\_\_\_  
Day/month/year

Copy provided to the participant \_\_\_\_\_ (initialed by researcher/assistant)

Parent/Guardian has signed an informed consent \_\_\_ Yes \_\_\_ No \_\_\_ (initialed by researcher/assistant)

**Appendix C: The Physical Self-Inventory –Very Short Form-Intellectual Disability**  
(Maiano et al., 2009)

Participant Name:

Interviewer Name:

Date:

Start Time:

End Time:

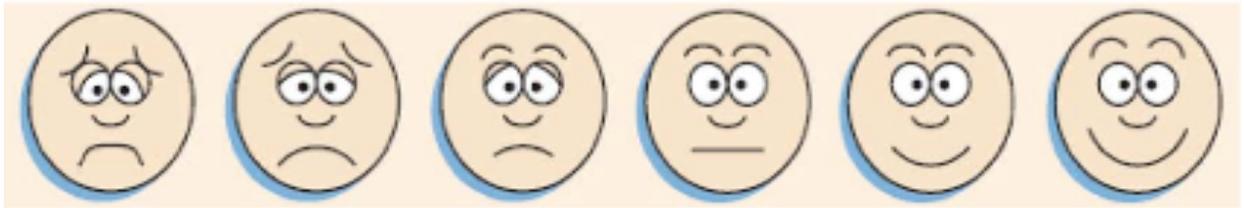
Interviewer instructions: Read the statement aloud and then say, ‘How much is that like you? Not at all like me, very little like me, somewhat like me, enough like me, a lot like me, or entirely like me.’ while pointing to the faces that correspond to each answer (printed on the following page).

*Circle participant’s response:*

1. I like myself	0	1	2	3	4	5
2. I am happy with everything I can do with my body	0	1	2	3	4	5
3. I am stronger than other people	0	1	2	3	4	5
4. My body is nice to look at	0	1	2	3	4	5
5. I can carry heavy things	0	1	2	3	4	5
6. I can run a long time without becoming tired	0	1	2	3	4	5
7. I am good at all sports	0	1	2	3	4	5
8. Everyone finds me good looking	0	1	2	3	4	5
9. I am happy with myself and with what I can do with my body	0	1	2	3	4	5
10. I can run ten times around a basketball court without becoming tired	0	1	2	3	4	5
11. I do things well in sports	0	1	2	3	4	5
12. I want to stay as I am	0	1	2	3	4	5

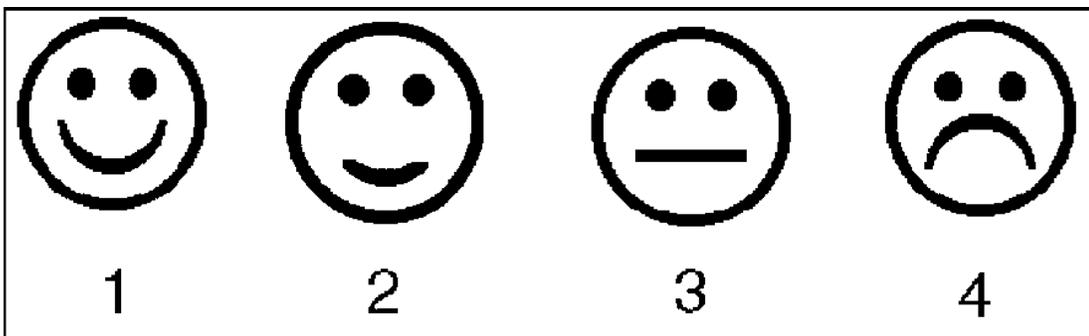
Interviewer notes:

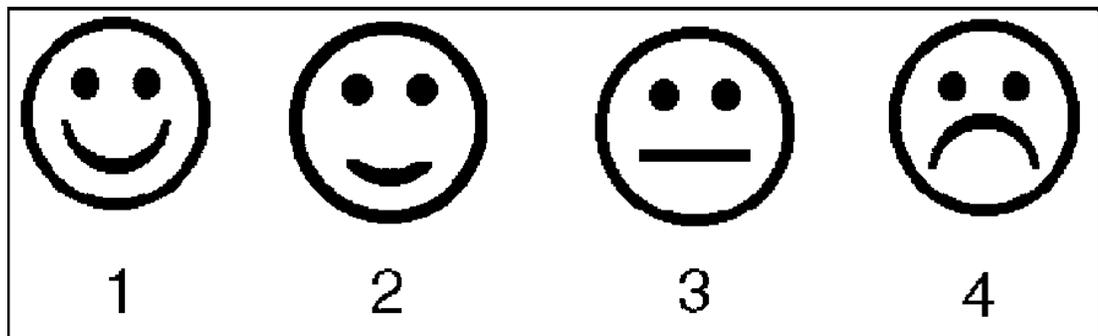
## Appendix D: Visual Cue Card for Physical and Social Self-Concept Scales



## Appendix E: Emotional Well-being at Home

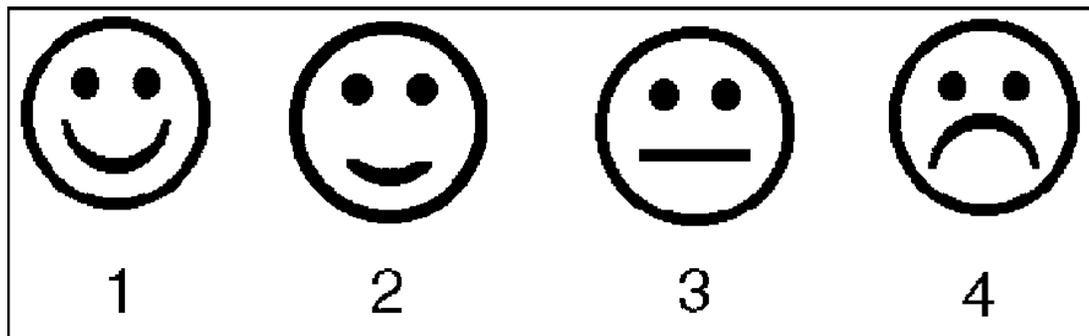
**At home...**



**Appendix F: Emotional Wellbeing at School/Work****At school/work...**

Appendix G: Emotional Wellbeing at Special Olympics

At Special Olympics...



**Appendix H: Emotional Well-being for Feeling Sad or Worried**

Sad or worried

**Appendix I: Emotional Well-being for Feeling Left Out**

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**Left out**

**Appendix J: Emotional Well-being for Feeling Helpless**

Helpless

**Appendix K:** Emotional Well-being for Feeling Confident



**Confident**