Is Measuring Best? Evaluating Report Derived Body Mass Index in Special Olympics Participants

By

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Is Measuring Best? Evaluating Report Derived Body Mass Index in Special Olympics Participants

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Abstract

To determine the proportion of overweight/obesity, studies save time and money by using reported height and weight for the calculation of body mass index (BMI). However, no studies have reported the validity of self and proxy-reported height and weight in persons with intellectual disabilities (ID). This study aimed to determine the validity of self and proxy-reported height and weight for the calculation of BMI in individuals with ID. **Manuscript 1 (Self-report):** Results demonstrate that self-reports from individuals with ID are valid, and can be used when physical measurement are not feasible. **Manuscript 2 (Proxy-report)**: Results show that proxy-reported height and weight for individuals with ID, specifically parents, were fairly accurate and may be used when physical measurements are not possible. **Conclusion:** The results from this study suggest that individuals with ID and their proxies can report height and weight. These results need to be confirmed using larger sample sizes.

Keywords: intellectual disability, overweight, obesity, body mass index, measurement, self-report, proxy-report

Kristin M. Dobranowski (2015)

Statement of Originality

I, Kristin M. Dobranowski, hereby declare that this thesis is, to the best of my knowledge, original, except as acknowledged in the text. I further declare that the material contained in this thesis has not been previously submitted, either in whole or in part, for a degree at this or any other university.

Kristin M. Dobranowski (2015)

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List of Abbreviations Used

ANOVA	Analysis of variance
BMI	Body Mass index
CSEP-PATH	Canadian Society for Exercise Physiology: Physical Activity, Fitness & Lifestyle
CVD	Cardiovascular Disease
DS	Down syndrome
DSM	Diagnostic and Statistical Manual for Mental Disorders
DXA	Dual-energy X-ray absorptiometry
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual Disability
NHANES	National Health and Nutrition Examination Survey
NPV	Negative predictive value
PPV	Positive predictive value
PWS	Prader-Willi syndrome
SD	Standard Deviation
WHO	World Health Organization

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1 INTRODUCTION

1.1 Introduction to Thesis

1.1.1 Intellectual disabilities

Intellectual Disability (ID) is widely defined as a limitation in both "intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills" (American Association on Intellectual and Developmental Disabilities, 2013). The disability originates before the age of 18. Down syndrome, fragile x syndrome and foetal alcohol syndrome are examples of conditions commonly associated with ID. The World Health Organization International Classification of Diseases (WHO-ICF) contributes to the definition by stating that disability is an umbrella term for impairments, activity limitations or participation restrictions in an individual's life (World Health Organization, 2001a). According to the WHO-ICF persons with disabilities, including ID, are not defined by their disability; rather, they represent a group that frequently requires supports in order to maximize their level of activity and participation in their daily pursuits (World Health Organization, 2001b).

There are severity levels of ID which can be categorized into mild, moderate, severe and profound. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), severity is determined by the level of supports the person with ID requires (American Psychiatric Association, 2013). There is a higher prevalence of people with milder forms of ID. A review proposed that the prevalence of mild ID is 34 per 1000, while the prevalence of more severe types of ID is 3.8 per 1000 (Roeleveld, Zielhuis, & Gabreëls, 1997). The overall prevalence of ID around the world is about 1%; it is highest in low to middle income countries and in children and adolescents (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011).

Individuals with ID not only experience limitations in their intellectual functioning and adaptive behaviour, they frequently experience complex health problems (Lunsky, Klein-Geltink, & Yates, 2013). For instance, they are more likely to be diagnosed with a range of chronic diseases including diabetes and chronic obstructive pulmonary disease (Lunsky et al., 2013). In addition, a large percentage of this population may experience psychiatric problems, and neurologic and sensory impairments (Bhaumik, Watson, Thorp, Tyrer, & McGrother, 2008; Lunsky et al., 2013). They may exhibit behaviour problems or experience limitations in mobility, communication, and language that may prevent or inhibit them from having their health issues properly addressed (Kerr, 2004). These limitations may influence their understanding of how to live a healthy life and may cause persons with ID to frequently rely on their caregivers for support (Bhaumik et al., 2008); for example caregivers may guide their grocery shopping habits or answer questions on their behalf at the doctor's office. People with ID have poorer health compared to people without ID, and have high levels of unmet health needs (Wilson & Haire, 1990). The high level of comorbidities and problems addressing their needs ultimately contributes to a shorter life expectancy (Bittles et al., 2002; Lunsky et al., 2013). Overall, many people with ID have complex health issues and commonly depend on their caregivers to help meet their needs (Bhaumik et al., 2008).

One specific and serious health condition individuals with ID experience is overweight/obesity. Although overweight/obesity is not considered an actual disease causing harm within our bodies (Katz, 2014), it contributes to other debilitating issues; it is considered the second leading contributor to death in the United States (Rimmer &

Wang, 2005). Overweight/obesity is a risk factor for type II diabetes, some cancers, osteoarthritis, and cardiovascular disease (CVD), leading to an increase in the risk for mortality (Haslam, Sattar, & Lean, 2006; World Health Organization, 2014).

The health of individuals with ID is further compromised by overweight/obesity because it is associated with decreased quality of life, influences the ability to form relationships, increases the risk of depression, and can decrease social and physical functioning (Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010). As the implications of overweight/obesity are so significant, the prevalence of overweight/obesity in persons with ID is of interest and should be made a priority.

1.1.2 Prevalence of overweight/obesity in persons with ID vs. the general population

General population

Overweight/obesity prevalence is extremely high in the general population, specifically in developed countries, contributing to serious health issues and death (World Health Organization, 2014). In Canada, the prevalence of obesity is 23.0% in adults and 36.0 % are overweight (Tjepkema, 2006), and 25.0% of female children and 31% of male children are overweight/obese (Tremblay et al., 2010). It is estimated that obesity represents 2.2% of all health care costs (Connor Gorber, Tremblay, Moher, & Gorber, 2007; Heart and Stroke Foundation of Canada, 2009). Although obesity rates are extremely high in the general population, they are even higher in persons with ID (De, Small, & Baur, 2008; Foley, Lloyd, & Temple, 2013; Lloyd, Temple, & Foley, 2012).

Adults with ID

In a recent study using directly measured height and weight of adult U.S. Special Olympians, obesity levels for males with ID across age groups were found to be 38.0-45.0%, which was 5.0-10.0% higher than measured data from the general population obtained from the National Health and Nutrition Examination Survey (NHANES) (Foley et al., 2013). The disparity was even higher among females with ID. Research found that 52.0-57.0% of adult females with ID were classified as obese which was approximately 20.0% higher than the general population (Foley et al., 2013).

These results have been found to be consistent with studies from other developed countries. Four studies which relied on data other than self-reports/proxy-reports, found that obesity rates in New Zealand, the Netherlands, England and Hong Kong were significantly higher in adults with ID. In New Zealand, researchers found 51.0% of the ID population were obese, compared to 30.0% of the general population (Stedman & Leland, 2010). In the Netherlands, they found obesity in 26.0% and overweight in 38.0% of persons with ID, which was 10% higher than the general population (de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012). Researchers in England and Hong Kong also found obesity was higher in ID than the general population; in addition, women with ID were twice as likely to be obese than men with ID (Bhaumik et al., 2008; Chan & Chow, 2010).

The study by Stancliffe et al. (2011) from the U.S. reported contradictory findings. They found that 62.2% of their sample of people with ID was overweight or obese and 33.6% were obese. Stancliffe's general population results, like Foley et al. (2013), came from the most recent NHANES data (2007-2008). Compared to the general population (35.5%), the prevalence of obesity was higher for women with ID (38.9%). Whereas, the prevalence of obesity for men with ID was actually lower (29.4 %) than the general population (32.2%) (Stancliffe et al., 2011). The different results by Stancliffe et al. (2011) may be attributed to the fact that data on height and weight were not measured but rather collected from individual records. For example, family members reported height and weight in inches and pounds on behalf of the participants with ID, unlike the other studies which relied on directly measured data. This stresses the importance of determining the validity of reported versus measured information related to overweight and obesity in people with ID. Overall, the studies show that adults with ID have consistently higher prevalence of overweight and obesity than the general population.

Children with ID

Research based on directly measured data found that in a global sample of children and youth with ID who participate in Special Olympics, 30.0% were either overweight or obese (Lloyd et al., 2012). Rates of overweight and obesity were highest in North America compared to other countries and regions (Latin American, Africa, Europe and Asia). For example, overall 54.3% of North American females were overweight or obese and 47.7% of North American males were overweight or obese. The international sample of children and youth with ID showed that obesity levels ranged across the regions from 4.6% to 32.6% and an additional 4.1% to 26.3% of the sample were classified as overweight (Lloyd et al., 2012). In another international sample of over 34 countries where children were selected from schools, it was found that overweight ranged from 5.1% to 25.4% and obesity ranged from 0.4% to 7.9%. (Janssen et al., 2005).

Similar to results from Lloyd et al. (2012), measured data collected from children and adolescents with ID in Australia also found a greater risk of overweight or obesity compared to children and youth of typical development (De et al., 2008). In Australia, 25.0% of children were overweight and 15.0% obese, which was much higher than the general school population which found 17.0% were overweight and 6.0% obese.

Overall, it is concluded that persons with ID have a much higher prevalence of overweight and obesity, compared to the general population. Many factors contribute to their increased risk of weight gain and some have been explored in the literature.

1.1.3 Factors associated with increased risk for overweight/obesity in persons with ID

The high rates of overweight/obesity in persons with ID have been attributed to genetic and other disorders associated with ID (Gravestock, 2000; Pogson, 2012), sex (Melville, Hamilton, Hankey, Miller, & Boyle, 2007), medication use (de Kuijper et al., 2010; Lunsky et al., 2013), low physical activity levels (Salaun & Berthouze-Aranda, 2011; Temple, Frey, & Stanish, 2006), severity of ID (Robertson, Emerson, Gregory, Hatton, Turner, et al., 2000), and unhealthy nutritional habits (Bandini, Curtin, Hamad, Tybor, & Must, 2005; Pogson, 2012).

Specific ID etiologies

Research has found that 77.8% of females and 62.0% of males with Down syndrome (DS) were above the recommended weight categories (Melville, Cooper, McGrother, Thorp, & Collacott, 2005). Bhaumlik et al. (2008) also found that the prevalence of obesity among people with ID was more prevalent when an individual had DS. However, Melville et al. (2007) state that although women with DS had higher BMI and obesity rates than other people with ID, no significant difference were detected between men with DS versus other men with ID.

The research conducted on obesity and obesity-related secondary conditions in American adolescents with ID and developmental disabilities also found that adolescents with autism were two to three times more likely to be obese than adolescents with typical development (Rimmer et al., 2010). For example, 24.6% of youth with autism were obese and 42.5% were overweight, whereas 13.0% and 28.8% of youth with typical development were obese and overweight (Rimmer et al., 2010).

Lastly, Prader-Willi syndrome (PWS) is a complex neurodevelopmental genetic condition that has many characteristics which include neurologic, developmental and behavioural differences caused by gene mutations (Pogson, 2012). One of the key features of PWS is hyperphagia (Pogson, 2012), a phase of overeating which begins in childhood. Young individuals with PWS also experience lower metabolic rates, causing them to feel hungry even after overeating (Pogson, 2012). The prevalence of obesity in PWS is thus very prominent as these manifestations contribute to weight gain. Ultimately, obesity is more prevalent in PWS than other causes of ID (Melville et al., 2007), and is considered a major phenotypical feature of this condition (Pogson, 2012).

Medication use

Persons with ID are often overmedicated with psychotropic medications (de Kuijper et al., 2010). It is estimated that between 30.0-50.0% of adults with ID receive psychotropic medications (Robertson, Emerson, Gregory, Hatton, Kessissoglou, et al., 2000) such as antidepressants, antipsychotics, and antiepileptic drugs (Virk, Schwartz, Jindal, Nihalani, & Jones, 2004). In a sample of Ontario adults with developmental disabilities who receive income from the Ontario Disability Support Program, approximately 60.5% of the adults were dispensed medications: of those given medications, over 20.0% were antipsychotics (Lunsky et al., 2013). These drugs are formally indicated for psychotic disorders, but are often prescribed outside of their licenced use for behavioural symptoms such as aggression in persons with ID, a practice referred to as off-label use (de Kuijper et al., 2010). It is well established that these types of drugs have metabolic consequences (de Winter et al., 2012) that contribute to weight gain (Virk et al., 2004). It is therefore suggested that the high use of anti-psychotics increases the risk of being overweight or obese (de Winter et al., 2012). Consistent with this, researchers in France found that two times more males with ID who were on anti-psychotic medication were classified as overweight compared to males who were not on this medication (Bégarie, Maïano, Leconte, & Ninot, 2013). Clearly, medication use in persons with ID can contribute to their weight gain and the prevalence of overweight/obesity.

Physical activity and nutritional habits

Research has found that participation in physical activity tends to be lower among persons with ID (Temple et al., 2006). The opportunities to engage in physical activity are not as plentiful (Yamaki, 2005) as for the general population. It has also been found that adolescents with ID have lower physical fitness (Salaun & Berthouze-Aranda, 2011), poor coordination, and are often not included in team sports (Bandini et al., 2005), which influences motivation to participate in physical activity.

Nutritional intake is another reason for overweight/obesity in persons with ID. As previously stated, persons with PWS experience overeating during a phase called hyperphagia (Pogson, 2012). People with PWS lack normal appetite control mechanisms and this can contribute to weight gain during their entire lives (Pogson, 2012). In addition, children with disabilities are often given food as behavioural reinforces (Bandini et al., 2005) which may lead to overeating and weight gain through increased caloric intake outside of meals. It has also been hypothesized that persons with ID experience other endocrine abnormalities like hypothyroidism at higher rates and exhibit poorer eating behaviours (Bhaumik et al., 2008). A study examining the overall health of adults with ID in Spain, found that the samples cholesterol consumption was too high, fibre was too low, and healthy fat consumption was below recommended values (Soler Marin & Graupera, 2011).

Other explanations

Some additional reasons to explain the high prevalence of overweight/obesity in persons with ID include sex, age, and level of ID, lifestyle factors, education, and living environment. Like the general population, sex and age influences the risk for weight problems in persons with ID. Women with ID are at a greater risk (12.0-17.0% higher) of becoming overweight or obese compared to men with ID (Melville et al., 2007). However, the effect of age on overweight/obesity risk in persons with ID, is not the same as for the general population. The general population's prevalence of overweight/obesity gradually increases with age, starting at around 34-37 years. In contrast, the risk of overweight/obesity in persons with ID starts 20 years earlier; this also means persons with ID may have an earlier onset of obesity-related diseases (Melville et al., 2007).

The prevalence of overweight/obesity in persons with ID is highest in persons with mild to moderate ID (Hove & Havik, 2010). The prevalence ranged from 9.0-30.0%

higher than adults with severe or profound intellectual disabilities (Hove & Havik, 2010). In addition, persons with ID who live with family or in less restrictive environments such as living independently are at a greater risk of overweight/obesity (Yamaki, 2005). In these living situations, persons with ID may be less conscious about the health risks associated with overweight/obesity. They may also not gain the knowledge of health risks in their everyday experiences (Bhaumik et al., 2008); as well, they often have lower income which limits food choices when shopping (Yamaki, 2005).

Overall, the higher rates of overweight/obesity in individuals with ID are a concern. Persons with ID already experience complex health problems, some syndrome-specific, and they are often not properly identified and addressed(Kerr, 2004). Consequently, the implications of overweight/obesity only add to the complexity of this population's health status, and therefore, needs to be addressed.

1.1.4 Methods for assessing body adiposity

The general population

To determine the prevalence of overweight/obesity, large population studies rely on body mass index (BMI), an index of height and weight commonly represented in kg/m^2, to classify underweight, normal weight, overweight, and obesity in children and adults (Morrissey, Whetstone, Cummings, & Owen, 2006; World Health Organization, 2000). BMI is claimed to be a useful measure of overweight/obesity for large populations and can be used to estimate the prevalence of overweight/obesity (World Health Organization, 2000). However, there is controversy around the sole use of the BMI calculation, as it does not take into consideration abdominal obesity. BMI is specifically not suited for people with a lot of muscle (e.g. high level athletes, body builders), as it produces an inaccurate estimate of overweight/obesity, since muscle adds weight to the individual (Kravitz, 2010). The sole use of BMI as a surveillance tool has not been recommended by some authorities as it may lead to an under or overestimation of overweight/obesity and its associated health burdens (Walls et al., 2011).

Persons with ID

Consistent with studies conducted in the general population, research on overweight/obesity prevalence in people with ID relies on height and weight measurement for a BMI calculation. As reported earlier, persons with ID have a higher prevalence of overweight/obesity compared to the general population (Foley et al., 2013; Lloyd et al., 2012). It is therefore very important to understand the best ways to reflect body composition in persons with ID.

In 2010, one study examined the usefulness of BMI as an indicator of adiposity among adults with ID (Temple, Walkley, & Greenway, 2010). Weight and height were measured by trained assistants, and were used to calculate BMI. Following measurements, total body bone density and soft tissue composition were measured using a dual-energy X-ray absorptiometry (DXA) machine. Percent of body fat, fat mass and lean mass from DXA and BMI were examined to determine how they correlated. Upon analysis, the authors concluded that BMI was a reasonable indicator of adiposity in adults with ID (Temple et al., 2010). More recently, a review of six articles assessing body composition for people with ID was published (Casey, 2013). Assessment methods included height and weight measurement for BMI, waist circumference, tibia length, and bioelectrical impedance analysis, skin fold thickness, and anthropometric girth measurements. The review found that BMI was a good option for assessing body composition as it showed good agreement with more accurate tests such as the DXA; however, Casey (2013) also stated that well-conducted research examining the validity of body composition measures in persons with ID is limited, suggesting more research is required.

1.1.5 Common methods for collecting height and weight data

Population surveillance is an important component for reducing the prevalence of overweight/obesity around the world. In order to determine overweight/obesity prevalence in large samples, it is often unfeasible to use the gold standard of physical measurement, due to the costs and time required to complete (Connor Gorber et al., 2007; Morrissey et al., 2006). It is also difficult to obtain the information from medical records as health care professionals do not regularly record the height and weight of their patients (Booth, Prevost, & Gulliford, 2013). Consequently, the most common way of collecting height and weight for studies is through self-reported or proxy-reported height and weight for the calculation of BMI in both the general population (Connor Gorber et al., 2007; OECD, 2013), and in persons with disabilities (George, Shacter, & Johnson, 2011; Phillips et al., 2014; Rimmer & Yamaki, 2006). However, there are some limitations to self and proxy-reporting that must be considered in research, including memory bias and response bias (Connor Gorber et al., 2007). The common problems with self and proxy reporting raises the question: how valid are self and proxy-reported height and weight compared to the gold standard of direct measurement. The literature shows that in the general population, most self and proxy-reports for height and weight from adults and children lead to underestimated calculated BMI (Elgar & Stewart, 2008; Kuczmarski,

Kuczmarski, & Najjar, 2001; Morrissey et al., 2006). However, it is unknown if the reports for persons with ID under or overestimate the proportion of overweight/obesity.

1.1.6 Participating in research: Persons with ID and proxies

The literature shows that self and proxy-reported data is common; it makes collecting data from large populations for health and research purposes simple and feasible, regardless of its limitations. However, self-reported data in persons with ID is often avoided and substituted with proxy-reporting (Fujiura, 2012) as it is believed persons with ID have characteristics which decrease the validity of self-reports (Breau & Burkitt, 2009). It has been reported that the level of intellectual development may also affect self-reported data (Perkins, 2007). However, more research is needed on the validity of proxy-reports on behalf of people with ID. For instance, it has been found that the type of relationship between proxy and persons with ID may influence the validity of the proxy-reports for individuals with ID (Perkins, 2007), for example a parent or a paid staff caregiver. Other factors that may influence the validity of reports include proxy characteristics (e.g. age, sex, and education) and how long the proxy has known the individual (Magaziner, Bassett, Hebel, & Gruber-Baldini, 1996). Magaziner et al. (1996) found that proxy agreement with a subject's answers is generally better when the proxy was a male and living with the individual.

Recently, researchers, advocates and people with ID themselves have stressed the need to include persons with ID in research more often (Fujiura, 2012). Encouraging persons with ID to provide self-reports in research allows them an additional opportunity to become active agents in their lives, allowing their choices and self-determination to grow. With momentum increasing to include persons with ID in research, it is important to take note and validate these reports.

1.1.7 Conclusion

Overweight/obesity prevalence in the general population and in persons with ID is a pressing issue. There are many different reasons for the high prevalence in persons with ID including genetic factors, medication use, personal behaviours such as physical activity and nutrition, as well as other factors like living arrangements and education. To obtain overweight/obesity statistics, the gold standard is physically measuring height and weight to derive BMI. However, for surveillance of large populations, measuring height and weight is not feasible and thus researchers rely on self-reported or proxy-reported height and weight.

Researchers have yet to determine if persons with ID and their caregivers can accurately report height and weight. In addition to not collecting this information, we may also be excluding them from fully participating in society. The primary objective of this research is to better understand the accuracy of self and proxy-reported height and weight for derived BMI in persons with ID. The secondary objective is to understand how the validity of self-reports may differ based on the level of ID and how the validity of proxy-reports differ based on type of proxy relationship. This will potentially help promote more inclusion of persons with ID and their caregivers in health related aspects of their lives; in addition, it will improve the understanding of their overall health.

1.2 Proposed Theoretical Framework

1.2.1 Model overview

In 2001, The International Classification of Functioning, Disability, and Health (ICF) was endorsed by all World Health Organization (WHO) Member States (World Health Organization, 2001a). The WHO-ICF classification aims to provide a simple way of defining health and well-being for individuals with and without disabilities in an effort to improve communication between policy-makers, health care works, researchers, the public and persons with disabilities. The WHO-ICF explains that any individual can experience some degree of a health condition and also some degree of a disability (World Health Organization, 2002). When discussing disability, the WHO-ICF considers the individual, the environment and society, and these are described through changes in body function and structure, and in activities and participation. The WHO-ICF has moved from a focus on the impacts of diseases where health is understood to be possible only in the absence of disability (World Health Organization, 2002) towards a more neutral stance of what constitutes health (World Health Organization, 2001a). By providing a framework for measuring health care needs and the performance and effectiveness of health care systems, the WHO-ICF delivers an important classification system for obtaining reliable and comparable data on individuals in all populations.

1.2.2 Applications of ICF

In scientific research the WHO-ICF model (World Health Organization, 2001b), aims at universally classifying the activity and participation levels of individuals with disabilities, particularly in the roles of their social life (World Health Organization, 2002).

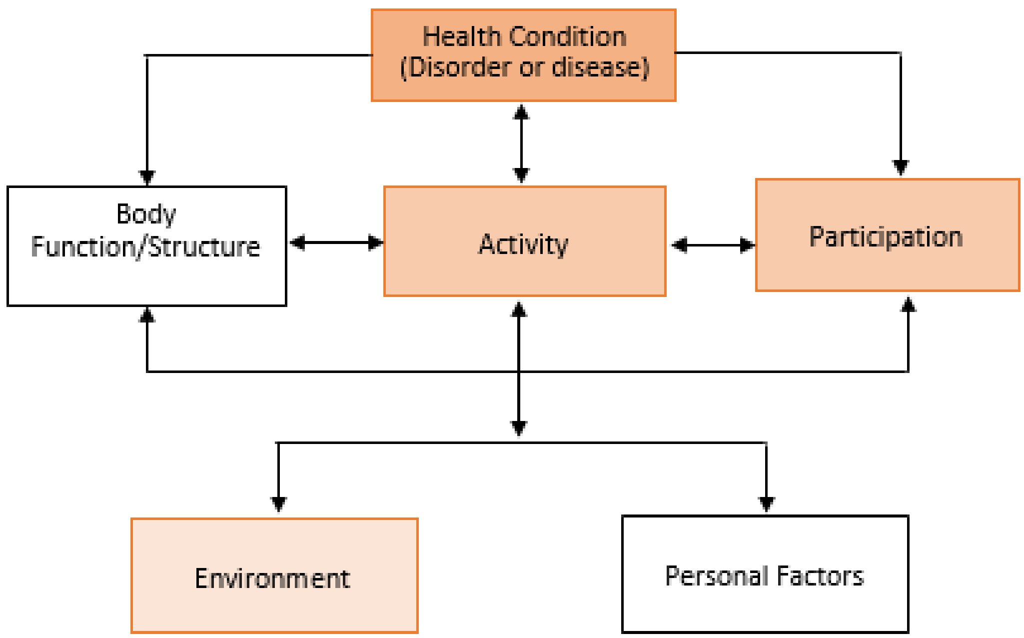
The WHO-ICF states that the completion of activities are influenced by performance and capacity qualifiers. For instance, persons with ID reporting their own height and weight may be limited by some aspect of their ID. One of the goals of this thesis research is to determine if persons with ID are able to report their own height and weight accurately for BMI; using the WHO-ICF terminology it is to determine if their capacities are in fact limited during the activity of reporting height and weight.

The WHO-ICF model states that participation is the degree to which one can take part in or influence life situations that are important (World Health Organization, 2014). However, participation in daily activities for individuals with ID may be influenced by environmental factors (World Health Organization, 2014) such as their parents, and direct supports persons etc. (Waninge, 2010). The act of reporting height and weight can be seen as an example of participation in daily activities. The presence of parents or other proxies can be seen as an environmental factor (World Health Organization, 2014) that acts as a barrier or a facilitator depending on the circumstances: it is a barrier if persons with ID are not given the chance to report their own height and weight. Similarly, a researcher or clinician asking for health information can be a barrier or facilitator depending on their attitude and understanding of abilities of persons with ID. This study gives persons with ID the opportunity to participate in answering questions on their own. Participation may improve feelings of positive social involvement (Waninge, 2010); it may provide an opportunity for more autonomy in providing information, contributing to a better self-image. Participation may empower persons with ID to take more ownership in their health and well-being, leading to a better quality of life.

Intellectual Disabilities, Reporting Health and ICF

Figure 1 is a diagram of the WHO-ICF model that will be used to classify the study population; each shaded coloured component is described in regards to persons with ID in this study.

Figure 1. World Health Organization-International Classification of Functioning, Disability, and Health model



Health condition

All of the participants in the current study were Special Olympics athletes, and were diagnosed with an intellectual disability. This study included participants with various causes and severity levels for their intellectual disability.

Activity

The activity component of the WHO-ICF is defined as the execution of a task or action by an individual, which may be limited by their "capacity" to execute a task, and their capacity may be influenced by some aspect of their disability (World Health Organization, 2001a). In the past, persons with ID were often not included in research and were not asked to respond in health settings as it was believed that their intellectual disability would influence the validity of their answers. By asking persons with ID to report their height and weight, the validity of their answers could be determined thus supporting their inclusion in health related communication.

Participation

The participation section of the WHO-ICF framework is described as involvement in a life situation (World Health Organization, 2001a). Persons with ID may experience restrictions in participation in life situations such as research and answering health questions due to the unknown validity of their reports. By participating in this health research, individuals with ID were introduced to the idea that height and weight are important to their health. The act of participation in research (regardless of the study results) gave the athletes an opportunity to learn more about their health.

Participation is also important for the caregivers or proxies of individuals with ID. Caregivers of persons with ID are often immersed in many aspects of their daily lives and are often asked to report on behalf of the individual. Proxy-reporting for individuals with ID is thus very common in health care settings and in health research. As caregivers often respond for persons with ID, they should understand the wants, needs, and health of the individual. As proxy-reporting is very common, this study will also examine if proxy-reporting is a valid way of collecting height and weight data.

Environmental factors

Environmental factors include the physical, social and attitudinal environment in which persons live their lives, and they can have a positive or negative effect on an individual's participation or capacity to perform actions. In this study, the individual environmental factors, such as the presence of a caregiver, may influence an individual with ID from answering health related questions on their own. Caregivers may assume the individual is not capable or does not understand, and frequently they will answer on their behalf. This study allowed individuals with ID to respond to questions regarding their health before a caregiver, allowing for the accuracy of their answers to be determined. Societal environmental factors also influence activity and participation levels of persons with ID. Attitudes and ideologies of doctors or researchers may prevent the use or answers of persons with ID. By determining the validity of reported height and weight in persons with ID, researchers and health professionals may be able to trust that their reports are valid, and thus persons with ID may be able to more freely participate.

Summary

In contrast to the medical model of disability, the WHO-ICF model, states that disability is not an attribute but a collection of conditions, and its management requires social action (World Health Organization, 2001b). Society as a whole must make modifications to encourage persons with ID to fully participate in their lives. As well, researchers and persons with ID should be encouraged to participate more in research; there are many barriers in recruiting individuals with ID in research, leaving limited epidemiological health studies (Lennox et al., 2005). If we do not know if this population can accurately report on health issues like their height and weight and are often excluded from research, we are restricting their full participation society.

1.3 Significance of this Research

Persons with ID are frequently left out of research, this is because research on persons with disabilities is considered low priority as they often have health conditions limiting their ability to participate (Sullivan et al., 2011). Also, researchers frequently exclude this group from studies done in the general population due to the effort needed to accommodate the disability. There may also be an assumption that results from the general population can be applied to this population. However, persons with ID are a unique group of individuals who deserve to be treated as such. This should be applied to the validity of self-reported and proxy-reported height and weight for persons with ID, in order to determine if current reports on overweight/obesity prevalence are accurate. For example, data on overweight/obesity is frequently collected using surveys in the general population and persons with ID. However, unlike the general population, the validity of self-reported and proxy-reported height and weight for BMI in individuals with ID has not been examined. Therefore, this study will fill a gap in the scientific literature regarding the validity of self-reported and proxy-reported height and weight in persons with ID.

The lack of literature in this area may be attributed to the belief that persons with ID cannot accurately self-report height and weight due to their disabilities. However, proxy reports are quite common in this population and they have not been validated either. There is a need for literature that verifies if both of these approaches are similar to direct measures and if they underestimate or overestimate levels of overweight/obesity, as there are significant consequences. For example, underestimating the level of overweight/obesity in this population could lead to a less clear understanding of the problem and its effects on comorbidities. Ultimately, with less attention paid to it by clinicians and researchers, categorizing persons with ID into wrong BMI groups could lead to incorrect conclusions in research and not enough resources may be allocated to address the problem.

1.3.1 Justification of methodology

Participants in this study included adolescents and adults, ranging from 12-55 years old. This wide age range is important because this study is the first of its kind, and a broad understanding of the situation for this population is required. Special Olympics athletes were chosen as the sample population (Special Olympics provides year round sports training and athletic competition for children and adults with ID); although they may be more active than their peers who are not athletes, recruiting a large group of persons with ID from the community in a short period of time was not feasible. Other studies on the topic tended to collect participants through schools and clinics, but for this study collecting participants from Special Olympics was the most economical way as sports teams often have large team numbers and meet on a regular basis during the summer.

Comparing self-reports to directly measured height and weight was also the most efficient way to have data for comparison. In the present study, obtaining a reliable scale and stadiometer was more manageable than obtaining measured height and weight data from medical records.

1.4 Research Objectives

1.4.1 Objectives

Manuscript 1

1. The principal objectives for manuscript 1 are:
   a) To determine the accuracy of self-reported height and weight and derived BMI in adults with ID.
   b) To determine the diagnostic performance (sensitivity, specificity, positive predictive value, negative predictive value) of self-report derived BMI for the identification of overweight/obesity
2. The secondary objective for manuscript 1 is to determine if severity level of ID influences the validity of self-reports.

Manuscript 2

1. The principal objectives for manuscript 2 are:
   a) To determine the accuracy of proxy-reported height, weight and derived BMI in adults with ID.
   b) To determine the diagnostic performance (sensitivity, specificity, positive predictive value, negative predictive value) of proxy-report derived BMI for the identification of overweight/obesity
2. The secondary objective for manuscript 2 is to determine if the type of proxy influences the validity of proxy-reports.

1.5 Thesis Organization

This thesis uses the manuscript format consistent with requirements of the Graduate Department of Health Sciences at the University of Ontario Institute of Technology. Sections 3 and 4 of this thesis address each of the objectives and stand alone as manuscripts that will be submitted for journal publication. Given the formatting of this thesis, the reader will find cases of repetition and differences in structure between chapters. The last section (5) of the thesis provides a summary of results, general discussion and conclusions.

2 LITERATURE REVIEW

2.1 Literature Review

2.1.1 Validity of self-report derived BMI data and its implications

Many studies around the world have examined the validity of self-reported height and weight in the general population (De Vriendt, Huybrechts, Ottevaere, Van Trimpont, & De Henauw, 2009; Jansen, Van de Looij-Jansen, Ferreira, De Wilde, & Brug, 2006; Linhart, Romano-Zelekha, & Shohat, 2010; Morrissey et al., 2006). Studies focused on adolescents and/or adults, to see how the self-reporting affects BMI categorization. Adolescents were primarily recruited from schools, whereas adults were recruited through surveys, and clinics etc. The results from the majority of these studies were conclusive: self-reported height and weight is not the best option for overweight/obesity prevalence data.

Self-reporting studies in adolescents in the general population

Morrissey et al. (2006) conducted a cross-sectional study investigating the relationship between self-reported and measured height and weight in adolescents. The authors recruited 416 students ranging from 10-16 years old, from 27 middle schools in North Carolina. Students were given surveys (Youth Risk Behaviour Survey) where they were asked to record their height and weight. Once they finished their survey a random sample of students was selected to have their height and weight measured and recorded. The authors calculated correlation coefficients for self-reported and measured data and used t-tests to compare self-reported and measured results. They found that correlation coefficients were high and the difference between self-reported and measured height were not significant. However, the mean self-reported weight was significantly lower than the mean measured weight, (1.5 kg difference, $p<0.001$) (Morrissey et al., 2006).

Due to self-reporting, 16% of the population was misclassified into an incorrect BMI category (Morrissey et al., 2006). Self-reports found 19.5% of the population was overweight, compared to 22.2% with measured data. Although the study found that weight was underreported by only 1.5 kg, the study concluded it would force 1 in 6 children to be misclassified into the wrong BMI categories. The authors therefore concluded that measured height and weight should be used when feasible (Morrissey et al., 2006).

Replicable studies during the same time period have been conducted in Dutch and Greek adolescents. Jansen et al. (2006), implemented t-tests, correlations, and sensitivity and specificity to analyze their data. They found that of over 5000, 12-13 year old Dutch adolescents under reported height by 1.5 cm and weight by 6.1 kg, which lead to a significant underestimation of BMI and overweight prevalence. Measured data found nearly 15% higher prevalence of overweight compared to self-reports (Jansen et al., 2006). The authors concluded that this population tends to underestimate BMI and the prevalence of overweight considerably. Even adjusting for relevant factors did not improve the validity of reports, and therefore the authors did not recommend the use of self-reported height and weight.

Tokmakidis, Christodoulos, & Mantzouranis (2007) used correlation coefficients, and t-tests to analyze data from approximately 680 Greek primary school students, with mean age of 11, and high school students with a mean age of 13. They found significant differences ($p<0.001$) between self-reported and measured height and weight; self-reported height and weight data lead to underestimated overweight and obesity by 5.7% and 5.2%. They found discrepancies increased when adolescents were heavier and were in high school, compared to grade school. The authors suggested that large studies determining overweight and obesity prevalence use measured data.

In a group of adolescents in Germany, mean age of 13.5 years old, students were recruited for a study from secondary schools (De Vriendt et al., 2009). At the schools the adolescents routinely underwent medical examinations by trained individuals. Before a scheduled examination, adolescents were invited to participate in the study and were given a questionnaire to fill out. The adolescents were not informed that the objective of the study was to determine the validity of their height and weight; this distinction was not clearly outlined in comparable studies. Following the questionnaire, the adolescents' height and weight were measured. Comparable to the other studies, De Vriendt et al. (2009) also used t-tests to detect significant differences between measured and reported height and weight, but also used Cohen's d to calculate effect size and the meaningfulness of the size of the differences. They used correlation coefficients to measure the level of association between self-reported and measured values, kappa statistics to examine the agreements between reported and measured BMI categories, and they calculated sensitivity and specificity. The researchers found that correlation coefficients were high for weight and height for BMI, indicating high agreement between reported and measured values. They found sensitivity values for overweight and obesity were low (55%, 73% respectively), but specificity was high (94.9%, 99.9%). In addition, it was found that both boys and girls underreported weight consistently, whereas height was overestimated by girls and underestimated by boys. Cohen's d values for all variables (reported and measured height and weight for BMI) were below 0.20, representing small effect sizes: this means that the differences between reported and measured results were trivial at a population level. But, when examined at the individual level, the differences were found to be quite large, and therefore, the self-reported values at the individual level were rendered not useful. Based on national and international cut-off values, 25% and 32% of adolescents had their BMI underestimated. This suggests that they were diagnosed as normal weight when in fact they were overweight or obese. In addition, the authors stated that if self-reported data were used to address the need for weight interventions, nearly 5% of the population would be missed and not included in programs addressing weight status (De Vriendt et al., 2009). Ultimately, like those before it, this study concluded that adolescents' self-reports cannot be substituted for measured values for BMI categories. It would lead to 13.2% of adolescents misclassified in an adjacent BMI category (De Vriendt et al., 2009).

Linhart et al. (2010) recruited 517 students (range 13-14 years old) in schools in Israel. They used correlations, t-tests, and calculated sensitivity and specificity for their analysis. The authors determined that self-reported height and weight in Israeli adolescents often underestimated the prevalence of overweight and obesity, thus misclassifying weight categories. For example, self-reports found 7.3% of females were overweight, whereas measured data found 10.3%. Self-reports in males found 5.3% were obese, while measurements found that 8.9% were obese; and for females 2.6% were self-reported obese, whereas measured data found 3.5%. These results were however not significantly different (Linhart et al., 2010). They also found that the mean differences in BMI values derived from self-reported and measured data in obese females was 4.40 +/- 4.34 kg/m^2 and for obese males 2.83 +/- 3.44 kg/m^2; the differences in BMI in most groups were found to be significantly different. It was also found that 54.9% of the population that was overweight or obese was classified correctly, and 6.3% of those with normal weight were categorized as overweight or obese. The sensitivity for self-reports to identify overweight/obesity was 50% in females and 58% in males, whereas, specificity was 96.5% in females and 91.3% in males (Linhart et al., 2010). The authors concluded that self-reports may be inappropriate, resulting in bias estimates of overweight and obesity, and they stated that some of the results did not reach statistical significance, possibly due to a smaller sample size. They suggested that self-reports may be useful if a valid correction formula was created (Linhart et al., 2010).

More recently, and in contrast to past studies, research in female African American adolescents (mean age 15.9), had slightly different conclusions about self-reported height and weight. Powell-Young (2012) implemented correlation coefficients and Bland-Altman analysis to compare the degree of agreement between self-reported and measured results. Weight in this study was underestimated by 1.8 kg and BMI by 1.5 kg/m^2. Overall, 14.0% of BMI categories were misclassified when using self-reported data. Powell-Young (2012) stated that although the self-reported height and weight were fairly accurate, there was enough potential error between the reported and true values and that this would affect the usefulness of substituting the reported for measured values. The author stated that using self-reported data instead of measured data should be at the discretion of health care providers and researchers based on the situation and goals; it may also be appropriate for large-scale prevalence studies, as self-reported data is easily attainable (Powell-Young, 2012).

Similarly, in a study of Portuguese adolescents, Fonseca et al. (2010), used the McNemar test to compare prevalence of overweight and obesity based on self-reported versus measured data, as well as t-tests to analyze the validity to detect differences between measured and reported height, weight and derived BMI. They found that adolescents self-reported weight was significantly lower ($p<0.05$) than measured. However, the prevalence of self-reported overweight and obesity (17.5% and 8.0%) compared to measured obesity (18% and 9.1%) was not significantly different. Researchers also found strong correlations between reported and measured values, with a standard error of measurement of 1.6 kg/m^2. This study determined that self-reported height and weight are valid alternatives for their measured values. Although at the individual level self-reported information for BMI was not recommended (Fonseca et al., 2009). Ultimately, this research found that self-reporting led to an underestimate of obesity; despite this it may be useful for large, epidemiological studies (Fonseca et al., 2009).

A study of Japanese 5th and 8th grade adolescents calculated correlation coefficients between continuous variables, and kappa statistics for agreement between calculated variables (Yoshitake, Okuda, Sasaki, Kunitsugu, & Hobara, 2012). While both males and females tended to under-report their height and weight, they found strong correlations between self-reported and measured data. Self-reported data found 13.6% of adolescents were overweight, which was not statistically significant from those found overweight with direct measuring (14.6%) (Yoshitake et al., 2012). The authors concluded that self-reported height and weight could replace measured values for this population; however, like previous studies, they suggested it should always be used with caution (Yoshitake et al., 2012).

Studies examining self-reported height and weight in adolescents have included large age ranges and demographics. It appears that more often than not, adolescent self-reports lead to an underestimation of weight and calculated BMI and thus overweight and obesity prevalence. However, the extent of the underestimations varied depending on the country and culture of the population, influencing some conclusions (Fonseca et al., 2009; Yoshitake et al., 2012). The statistical analysis methods for all of these studies were not consistent; for example some failed to report mean differences, others sensitivity and specificity. Some studies had very similar results (e.g. mean differences, percent misclassified) but the authors came to different conclusions. There was no consensus on what level of difference is suitable to accept or reject adolescents' self-reported versus measured height and weight data. Based on the overall recommendations from studies, it is concluded that adolescent self-reported height and weight should not be relied upon for prevalence data, unless results have been adjusted.

Self-reporting studies in adults in the general population

Kuczmarski et al. (2001), conducted a cross-sectional study using the NHANES III (1988-1994) questionnaire, to compare self-reported and measured height and weight for American adults 20 years and older. The authors implemented t-tests, correlation coefficients, and sensitivity and specificity analyses. Among younger adults, the researchers found that self-reported height and weight were similar to measured values and correlations were significant ($p<0.001$), but the validity of self-reports declined as adults aged (Kuczmarski et al., 2001). Like some studies in adolescents, self-report derived BMI was less than BMI values from measured data, and differences were statistically significant ($p<0.001$). Differences between measured and self-reported information differed depending on sex and age groups. Height was overestimated (0.04 to 2.70 cm), weight was overestimated by males (0.35 to 0.51 kg) and underestimated by females (0.56 to 1.49 kg), and for all groups BMI was underestimated (0.18 to 1.05 kg/m^2). Although this study showed a high specificity range across age groups (84 to 99%), the results for sensitivity were lower (73 to 95%). Ultimately, Kuczmarski et al. (2001), concluded that although self-reports were valid for classifying overweight and obesity in young adults, self-reports become less valid as persons age.

Similarly, in German adults ranging from 20-79 years old, a health survey was administered to determine how self-reported height and weight compared to measured data (John, Hanke, Grothues, & Thyrian, 2005). John et al. (2005), implemented chi-square tests, and Cohen's w for effect size, as well as, odds ratios and confidence intervals. The authors found that calculated BMI was underestimated, and similar to Kuczmarski et al. (2001), differences increased as adults aged. Self-reports underestimated overweight and obesity by 9.9% and 12.1%, and results were still significantly different after adjusting for specific variables including age, sex, education, employment type and income (John et al., 2005). Ultimately, the authors recommended that height and weight should be determined by measuring.

Results from across Canada from the Canadian Community Health Survey were accessed to obtain data on self-reported height and weight (Elgar & Stewart, 2008). Self-reports were compared to a randomly selected sub-sample whose height and weight were directly measured. Statistical analysis methods implemented included analysis of variance (ANOVAs), confidence intervals, and Bland-Altman plots (Elgar & Stewart, 2008). The results show that overweight and obesity were underestimated. For example, 15.3% self-reported obesity, whereas 22.9% were obese based on measured data (Elgar & Stewart, 2008). Differences between measured and reported height (0.88 cm), and weight (2.33 kg), led to an underestimate of BMI by 1.16 kg/m^2. Elgar noted that relatively small differences in weight and height obtained using the two methods led to meaningful differences in prevalence estimated derived from self-reports versus measured. Like Kuczmarski et al. (2001) and John et al. (2005), Elgar et al. (2008) concluded that self-reported height and weight should not be exclusively used as a tool for overweight/obesity surveillance.

Some more recent publications have found high degrees of validity from self-reported height and weight in adults. For instance, Brunner Huber (2007) studied women in Atlanta, Georgia; they were randomly selected from a medical clinic and their self-reported height and weight were compared to measured data. Mean differences were calculated to measure the accuracy of reporting, while paired t-tests and analysis of variances where used to evaluate statistical significance. The research found women underestimated their weight by 4.6 lbs and overestimated height by 0.1 inches, leading to a underestimated BMI of 0.8 kg/m^2 (Brunner Huber, 2007). The study found that, based on self-reports, 84.0% of the total sample was classified into the correct BMI category (Brunner Huber, 2007). The authors suggested that self-reports provided an accurate representation of the actual BMI among women of reproductive age.

In 2011, in a population of Korean adults, ranging from 30-70 years, a questionnaire was administered to obtain self-reported height and weight. They implemented t-tests, Pearson's correlation coefficient, kappa statistics, and sensitivity and specificity (Lee, Shin, Kim, Yoo, & Sung, 2011). On average, while height and weight tended to be slightly overestimated (0.41 cm and 0.12 kg), self-reported and measured values were highly correlated (>0.9). The degree of overestimation decreased as weight increased, which led to an underestimated BMI ranging between 0.05-0.08 kg/m^2 of the true BMI average (Lee et al., 2011). The prevalence of obesity based on self-reported values underestimated the true prevalence of obesity by only 1.1% in men and 2.0% in women, which were claimed as reasonably valid. In addition, the specificity was high for men and women (92.9% and 98.0%) while sensitivity was lower (87.6% and 83.6%) (Lee et al., 2011). Overall, Lee et al. (2011) concluded self-reported height and weight should be used with caution, especially with certain groups (e.g. those from older age groups and higher body weights), but they could be used when resources are limited in clinical and public health settings.

Similar results to Brunner Huber (2007) and Lee et al. (2010) were found in studies conducted using samples from the U.S. and Canada, and Austria. The first study with American and Canadian vegetarians implemented t-tests, correlation coefficients, sensitivity, specificity, and the kappa index (Bes-Rastrollo, Sabaté, Jaceldo-Siegl, & Fraser, 2011). They found that participants underestimated weight by only 0.2 kg and overestimated height by 1.57 cm, leading to an underestimated BMI of 0.61 kg/m^2. They also found that sensitivity of self-report derived BMI to detect obesity was 0.81, whereas specificity was 0.97 (Bes-Rastrollo et al., 2011). Ultimately, the authors suggested that data was valid enough for the vegetarian population for large epidemiological studies, although there was some underestimation of obesity (Bes-Rastrollo et al., 2011).

In 2012, Austrian adults were asked to fill out a questionnaire before their health check at a clinic. To analyze the data, the authors implemented Bland-Altman plots, and t-tests. Self-reported data found 12.5% of the population was obese, while measured data calculated 15.4% obesity (Großschädl, Haditsch, & Stronegger, 2012). For both sexes older than 55, weight was underestimated by 0.73-1.06 kg, height was overestimated by 1.44-1.46 cm and ultimately, calculated BMI was underestimated by 0.53 to 0.87 kg/m^2 (compared to only 0.2 kg/m^2 for individuals less than 35 year) (Großschädl et al., 2012). The authors concluded that adult self-reports are a reasonable measure for epidemiological studies, although obesity rates are most likely underestimated and could be improved with age-adjustments (Großschädl et al., 2012).

In 2007, a systematic review was published examining self-reported height and weight in adults compared to measured data (Connor Gorber et al., 2007). To assess the quality of the studies Connor Gorber et al. (2007) examined their validity, and types of significance testing, such as probability values, measures of variance and mean differences which they believe all studies should report on. The results found that weight and calculated BMI were underestimated, while height was overestimated; trends varied between men and women. However, the authors also found that the majority of the studies in the review were of poor quality, as they were missing relevant information and the review authors could not calculate an effect size (Connor Gorber et al., 2007). The review suggested improving the quality of reporting and concluded that self-reported measures can be used, but correction factors should be developed to improve the accuracy of information when direct measurements are not possible.

The preceding studies examining self-reported height and weight in adults used a wide range of ages and other demographics. The results of many of these studies showed that the majority of adults, like adolescents, tend to under report weight and over report height leading to an under-report of derived BMI. However, statistical analyses for validating self-reported versus measured height and weight data were not consistent. Like adolescents, the guidelines for rejecting or accepting self-report derived BMI data in adults of the general population are unclear. Consequently, like the results from Connor Gorber et al. (2007), we found that the literature was not consistent in their analysis, reports and conclusions. It remains uncertain what degree of difference between reported and measured weight and height for BMI can be considered acceptable. Therefore, due to the current inconsistencies in self-reported height and weight by adults, this data should not be fully relied upon for research purposes, unless adjustments are made.

2.1.2 Validity of proxy-report derived BMI data and its implications

Many studies around the world have also examined the validity of proxy-reported height and weight in the general population. Most studies have used children and/or adolescents in their samples and less often adults, to see how proxy-reporting affects BMI categorization. The results from the majority of these studies are conclusive: proxy-reported height and weight is not the best option for overweight and obesity prevalence data.

Proxy-reporting studies in adolescents in the general population

Several cross-sectional studies with large sample sizes have examined proxy-reported height and weight in children and adolescents. Huybrechts et al. (2006), examined parent reports for pre-school aged children aged 3-7. Participants were recruited from schools in Belgium and parents were asked to fill out a questionnaire, and then their children’s height and weight were measured by nurses. To analyze this study, the authors used mean differences, correlation coefficients, k-statistics, Bland-Altman plots and sensitivity and specificity. Statistically significant results showed that overweight and obesity were underestimated when parent reports were compared to measured data. The mean difference in weight was underestimated by 0.58 +/- 1.47 kg, BMI was also underestimated by 0.51 +/- 1.60 kg/m^2, and results were statistically significant ($p<0.001$). In addition, 4.7% of children were classified in a BMI category exceptionally different from the correct category, 31.3% were classified in the adjacent category and 64.0% were correctly classified (Huybrechts, De Bacquer, Van Trimpont, De Backer, & De Henauw, 2006). Therefore, the authors concluded that reports from parents were too inaccurate to be used in research and parents should be encouraged to measure their children before reporting values.

Scholtens et al. (2007) mailed out a questionnaire to Dutch parents with 4 year old children. The majority of parent respondents were mothers. To analyze their data, they implemented mean differences, correlation coefficients, Bland-Altman plots, kappa statistics and sensitivity and specificity. Results showed that reported and measured data corresponded well. For instance, over 92.0% of parents reported weight that was within 10.0% of the measured weight, but overall, prevalence of overweight was underestimated by 4.0%, causing 9.7% of children to have their BMI misclassified (Scholtens et al., 2007). Weight was underestimated by 0.1 kg, and height was overestimated by 0.4-0.5 cm and BMI was underestimated by 0.1kg/m^2. Although mean differences were small, this study concluded that caregiver reported height and weight should be questioned when used for estimating prevalence as they are often underestimated (Scholtens et al., 2007).

In a German study, Brettschneider et al. (2012) mailed a survey to parents of children aged 2-17. The authors calculated mean differences, correlation coefficients, kappa-statistics, and sensitivity and specificity. The authors reported that weight and derived BMI were under-reported across all age categories and discrepancies increased with the child's age. Researchers found that of those boys and girls that were overweight by measured data, 31.5% and 41.5% of them were misclassified as normal or underweight. The mean differences of measured and reported values ranged across age groups, specifically weight was underestimated by 2.23 to 0.24 kg and BMI was underestimated by 0.79 to 0.05 kg/m^2. Due to the range of mean differences, this study concluded that uncorrected parent reports for obesity surveillance are not recommended, and research should develop a correction formula (Brettschneider, Ellert, & Schaffrath Rosario, 2012).

Overall, studies on parent-reported height and weight for children and adolescents (2-17 years old) were consistent. Authors reported that parent reports underestimate overweight and obesity prevalence, and discrepancies may increase as children age and as weight increases. Unlike self-reported research, studies adjusting for variables were not found and therefore should be considered in future studies.

Proxy-reporting studies in adults in the general population

Proxy-reporting height and weight for adults is not common and therefore, the literature examining the validity is also scarce. In 2006, John et al. administered a health survey to adults 20-79 years old who self-report height and weight. In addition to self-reports, the survey requested another household member (ie. a proxy) to provide an estimated height and weight of the individual completing the questionnaire. Results showed that the household member underestimated the prevalence of overweight and obesity, especially when the target person was a female (John et al., 2005); researchers did not describe who the household member was. The authors ultimately concluded overweight and obesity data should be collected through measurement.

One other study was found that examined the validity of proxy-reporting in adults, but only examined reported weight. Malhotra et al. (2012) administered a survey to investigate the accuracy of proxy-reported weight for older Singaporean adults (60 years and older) with cognitive impairments, difficulty speaking/hearing, dementia or memory loss, or physical impairments, requiring them to rely on a proxy. The authors found that proxy respondents tended to report weight which lead to underestimating overweight (Malhotra, Chan, & Østbye, 2012). Offspring proxies were the most accurate, whereas other proxy responders such as other relatives tended to overestimate weight on average by almost 3 kg. Researchers, however, concluded that proxy-respondents for older adults, especially if proxy was an offspring, provide a fairly accurate estimate of weight (Malhotra et al., 2012).

No studies definitively examining the validity of proxy-reported height and weight of adults could be found (including adults with any type of disability). Ultimately, since the literature on proxy-reporting height and weight for adults in the general population is scarce, a conclusion cannot be made about the validity of such reports.

2.1.3 Reporting health for people with ID

Validity of self and proxy-reporting health in individuals with ID

As previously stated, individuals with ID have many complex health needs. In order for their needs to be addressed, they must be expressed and understood by health care providers. However, problems with communication and memory are a common manifestation of intellectual disability (Breau & Burkitt, 2009; Vicari, 2001) and these factors may make their self-reported data less accurate. Researchers have examined persons with ID with respect to self-reports for pain, health behaviours and body image and have compared them with proxy reports, and direct measurements to determine the validity.

In a review article, Breau et al. (2000) assessed pain in children with intellectual disabilities. The authors state that limitations in communication and behaviour in persons with ID may make it difficult to assess their pain, (Breau & Burkitt, 2009). While it was stated that self-reporting was an option for some high functioning children, observing participants for evidence of pain was recommended. After analyzing the literature Breau et al. (2000), found that self-reporting can be the most direct way to obtain information about pain, but there was little evidence to support the regular use of self-reports for children with ID. The authors concluded that young persons with ID have limitations which may influence the validity of self-reports and suggested that parent reporting may be the most valid option to understand pain and coping abilities of young persons with ID.

In 2002, researchers examined the validity of staff (proxy) reports, compared to self-reports of health behaviours, complaints, and medications among adults with mild ID

(Lunsky, Emery, & Benson, 2002). Although adults with ID are at a higher risk for health problems compared to the general population, Lunsky et al. (2002) reported that there is little research examining self-reports in persons with ID. In this study, researchers found that adults with mild ID were able to accurately report on information related to their health. For example, they accurately described their needs and were able to explain why they took medication; results were consistent with staff reports, but this study did not examine the validity compared to medical records (Lunsky et al., 2002). Nevertheless, this research demonstrates that adults with ID have a reliable and significant outlook to offer about their health and future researchers should investigate the use of both proxy-reports and self-reports.

In 2012, researchers examined the validity of self-reported health problems and pain by adults with ID and compared them to reports from their caregivers (Turk, Khattran, Kerry, Corney, & Painter, 2012). The researchers asked the participants what they thought of their body size, for example, “just right”, “too big” and “too small” (Turk et al., 2012). The height and weight of each participant was also collected to determine their BMI. The results show that the perceived body images and actual BMI were somewhat different. For instance, the BMI of 10 participants was in the obese range, but only 4 participants reported themselves as “too big” (Turk et al., 2012). In addition, 66.0% of the population felt they were just right, whereas only 35.0% participants had a BMI in the normal range and 18.0% thought they were “too big”, but 63.0% of the population was overweight or obese (Turk et al., 2012). It was also found that 43 of 59 participants self-image reports matched with the care giver BMI reports (Turk et al., 2012). Although Turk et al. (2012) showed that adults with ID can report their health problems, the validity of reporting their body image did not significantly correspond to their measured BMI.

Similarly, Reel et al. (2013) explored body image and BMI in Special Olympics athletes. First, height and weight were measured to determine BMI, and body image perceptions were obtained through interviews. For body image, Special Olympics athletes were shown silhouettes and they were asked which picture represented their current figure and results were compared with their measured BMI. Reel found that 71.0% of female athletes and 67.0% of males athletes were not happy with their current body size and of that 51.0% of females wanted to be smaller, and 37.0% of males also wanted to be smaller (Reel, Bucciere, & SooHoo, 2013). From this study it is clear that persons with ID are aware of their body size, and are conscious about their weight; they are also willing to learn and work on changing their body size and shape. Although not all have an accurate picture of their actual body size, body concerns are present. This suggests that some persons with ID understand the concept of height and weight and should be involved in reporting their own information.

2.1.4 Encouraging self-reporting in persons with ID

Persons with ID have characteristics which can influence the validity of self-reports; these concerns are similar to those in other populations with cognitive impairments such as patients with dementia (Fujiura, 2012). Fujiura (2012) explains that even though self-reported health is important for the evaluation of health, it is ignored and often substituted with proxy-reporting for people with ID. However, the author states that self-reports are very important as they are essential to evaluate need for care. In addition, Fujiura (2012) states that by encouraging self-reporting, persons with ID are able to act and become agents in their own lives. The author explains that self-reports may not be appropriate across the spectrum of abilities in persons with ID, but it allows values such as choice and self-determination to grow (Fujiura, 2012). Ultimately, there is a need to move beyond proxies for evaluating health in persons with ID and focus on self-reports (Balboni, Coscarelli, Giunti, & Schalock, 2013).

Even though these studies are not examining self-reported or proxy-reported height and weight in persons with ID, the referenced literature about the validity of reporting on other health issues in persons with ID should be taken into consideration when conducting further studies. Some of the literature recognizes that self-reports for persons with ID are not valid; others suggest they are compatible with proxy reports depending on the type of the ID (Fujiura, 2012) and the type of data being collected. Nevertheless, health research in persons with ID should consider the statements presented by Fujiura et al. (2012) and should find ways to implement self-reporting in addition to proxy-reporting in persons with ID; this will be taken into consideration for the current study.

The research question for this study was formulated with the specific intention of designing research that encourages choice and self-determination among the participants with ID.

2.1.5 Summary

Validity of self and proxy-report derived BMI data in individuals with ID

Although many studies rely on proxy and self-reports for BMI when collecting data, no studies were found that examine the validity of self-reported and proxy reported height, weight and derived BMI in individuals with ID. The only research found regarding reporting and BMI in persons with ID examined the validity of self-reported body images (Reel et al., 2013; Turk et al., 2012).

In 2005, one study measured height and weight for obesity prevalence in persons with disabilities; they compared results with obesity rates from self-reported height and weight in persons with disabilities from other sources (e.g. 1994-1995 National Health Interview Survey (NHIS) (Rimmer & Wang, 2005). Based on their results, Rimmer & Wang (2005) suggested that self-reported height and weight from persons with ID were not as accurate as measured data, and the disparities were greater than differences found in the general population. However, this study did not focus on individuals with ID and did not specifically examine the validity of reported height and weight for derived BMI.

The large gap in the literature regarding the validity of self and proxy derived BMI is concerning. In addition, obesity rates in this population are apparently very high, however, the lack of physical evidence and research on how to obtain valid results on obesity from large populations of persons with ID calls into question some of the methods used for far. In order to determine if the data collected on overweight and obesity is accurate for this population, the validity of self and proxy reporting height and weight in persons with ID must be determined.

3 MANUSCRIPT 1

3.1 Abstract

Adults with Intellectual disabilities (ID) experience high rates of overweight/obesity, which add to the complexity of their health. To obtain overweight/obesity data, large studies rely on self-reported height and weight to derive body mass index (BMI), a measure of adiposity. The validity of self-reported height and weight for BMI has been examined in the general population, but not in adults with ID. The objective of this study was to determine the accuracy of self-reported height, weight and derived BMI and determine the diagnostic performance of self-report derived BMI for the identification of overweight/obesity. A second objective of this study was to determine the validity of self-reported height and weight in individuals with ID based on the level of ID. Height and weight data were collected at Special Olympics Ontario events, and were measured using standardized equipment and procedures. A total of 40 participants were asked to report their height and weight; afterwards their height and weight were measured, and their BMI categories were determined. Results addressing the primary objective found the mean differences in measured and reported height, weight and derived BMI (3.35 cm, 0.25 kg, 0.12 kg/m^2). The sensitivity and specificity of BMI based on self-report measures were 92.9% and 75.0% respectively. This suggests that little misclassification is associated with using self-reported measures. Findings addressing the secondary objective found that self-reports from persons with mild and moderate ID were accurate. The sensitivity and specificity of BMI based on self-report measures of individuals with mild ID were 91.7% and 72.7% respectively. The results of this study indicate that self-reported height and weight for BMI calculation in individuals

with ID may be useful when physical measurement is not feasible; future research with larger samples is necessary.

3.2 Introduction

3.2.1 Intellectual disability

Intellectual disability (ID) is characterized by limitations in intellectual functioning and adaptive behaviour (American Association on Intellectual and Developmental Disabilities, 2013). In the general population, the prevalence of ID is estimated at 1% (Maulik et al., 2011). Commonly, to measure intellectual functioning an IQ test is performed, and other standardized tests are used to determine limitations in adaptive behaviour (American Association on Intellectual and Developmental Disabilities, 2013). The challenges persons with ID face in adaptive behaviour influence everyday social and practical skills.

Persons with ID experience limitations in communication and comprehension (Kerr, 2004) which may influence their ability to live a healthy life and forces them to frequently rely on caregivers for support, even into adulthood (Bhaumik et al., 2008). Compared to individuals without ID, individuals with ID have reduced access to quality health care which may be associated with their poor health status (Wilson & Haire, 1990). It has been found that individuals with ID have an increased risk to develop overweight/obesity (Foley et al., 2013; Rimmer & Wang, 2005; Temple, Foley, & Lloyd, 2014), chronic diseases such as diabetes and cardiovascular disease (Lunsky et al., 2013). Becoming more informed in their healthcare and advocating for their health is likely to improve the health outcomes of individuals with ID. Evidence suggests that that individuals with ID are able to be active agents regarding their health and health care (Fujiura, 2012) and health professionals should strive to encourage active participation whenever possible.

3.2.2 Overweight/obesity in adults with ID

Adults with ID experience high prevalence of overweight and obesity. For example, the prevalence of obesity in males with ID who participate in the United States Special Olympics (38.0-45.0%) was 5% to 10% higher than in the general population (Foley et al., 2013). The prevalence of obesity was even higher among women with ID (52.0-56.0%) which is nearly 20.0% higher than the general population (Foley et al., 2013). Similarly, in an international sample of adult Special Olympians, 24.7% were overweight, and 36.1% were obese (Temple et al., 2014). It was also found that the prevalence of obesity was particularly high among Special Olympian women, and Special Olympians from North America (Temple et al., 2014). Other developed countries have reported consistently higher prevalence of overweight and obesity in adults with ID compared to the general population. For example, 51.0% of persons with ID in New Zealand were obese, compared to 30.0% of their general population (Stedman & Leland, 2010), and in the Netherlands 38.0% were overweight, which was 10.0% higher than the general population (de Winter et al., 2012). Overall, studies show that adults with ID have consistently higher rates of overweight and obesity compared to the general population.

Overweight/obesity can seriously impact health. For example, being overweight or obese is associated with an increased risk of developing cardiovascular or metabolic diseases (Haslam et al., 2006; World Health Organization, 2014). As well, overweight/obesity can negatively influence an individual psychologically, socially and economically (Bhaumik et al., 2008). The etiology of overweight/obesity (and its health consequences) in individuals with ID is multifactorial and associated with genetic disorders (Gravestock, 2000; Pogson, 2012), medication use (de Kuijper et al., 2010; Lunsky et al., 2013), physical inactivity (Salaun & Berthouze-Aranda, 2011; Temple et al., 2006), nutritional habits (Bandini et al., 2005; Pogson, 2012), sex (Melville et al., 2007), and severity of ID (Robertson, Emerson, Gregory, Hatton, Turner, et al., 2000). Overall, the higher rates of overweight/obesity in adults with ID are a concern. Persons with ID commonly experience health problems and are often faced with challenges in their everyday lives adding to the complexity of their health. It is therefore important to ensure that methods used to obtain information of overweight/obesity are valid.

3.2.3 Body mass index as a measure of body adiposity

Body mass index (BMI) is a common method to assess body adiposity; it is an index of height and weight commonly represented in kg/m^2. BMI is used to classify individuals as underweight, normal weight, overweight, and obese (Morrissey et al., 2006; World Health Organization, 2000). BMI has been classified as a useful measure for collecting overweight/obesity prevalence in large populations (World Health Organization, 2000). It is important to collect this data from large populations because it allows researchers and health professionals to monitor changes in prevalence over time, and informs the need for public health interventions. However, it has been suggested that BMI may over or underestimate overweight/obesity and its associated health risks (Walls et al., 2011).

BMI obtained through direct measurement has been identified as a valid measure of adiposity in individuals with ID (Temple et al., 2010). In their study, Temple et al., compared BMI to the dual-energy X-ray absorptiometer (DXA) which is a validated measurement technique for adiposity. The authors reported that the BMI accounted for a large percentage (83.0%) of variance in total body fat determined by DXA (Temple et al., 2010). Similar results were found in a review study examining body composition methods for people with ID. The review concluded that BMI is a viable option to measure body adiposity in individuals with ID, as it showed good agreement with accurate tests such as the DXA (Casey, 2013).

3.2.4 Self-reporting for overweight/obesity prevalence

Overweight/obesity are serious conditions that affect the overall health and quality of life of persons with ID. It is not always practically and economically feasible to measure height and weight to derive BMI in large populations (Connor Gorber et al., 2007). Therefore, height and weight data is often obtained using self-reports (Connor Gorber et al., 2007; George et al., 2011; OECD, 2013; Rimmer & Yamaki, 2006). However, there are concerns about the validity of self-reported data because it may be influenced by memory bias, and response bias (Connor Gorber et al., 2007). Specifically, in individuals with ID it is believed that the level of intellectual development may affect self-reported data (Perkins, 2007).

Many studies have examined the validity of self-reported height and weight in general population samples of adults (Elgar & Stewart, 2008; John et al., 2005; Kuczmarski et al., 2001). These compared measured versus reported height, weight and calculated BMI. Studies consistently report that weight was underestimated, and height overestimated; leading to an underestimation of BMI. For example in a study conducted in Canada among those 12 years and older, it was found that the difference between measured and reported height was overestimated by 0.88 cm, weight was underestimated by 2.33 kg, and BMI was underestimated by 1.16 kg/m^2 (Elgar & Stewart, 2008). The authors concluded that self-reported height and weight should not be used exclusively as a tool for overweight/obesity surveillance. Similarly, in a study of German adults, a health survey was administered to determine the validity of self-reported height and weight (John et al., 2005). The researchers found that self-reported data underestimated the prevalence of overweight and obesity by 9.9% and 12.0%, even after adjusting for confounding variables. The authors concluded that height and weight for overweight/obesity data, should be determined by direct measurement (John et al., 2005).

In another study of American adults, researchers found that the BMI derived from self-reported height and weight was underestimated compared to measured BMI. The differences between measured and self-reported height, weight and BMI were 2.50 cm, 1.43 kg, 1.37 kg/m^2 respectively (Kuczmarski et al., 2001). Unlike the previous studies, this study concluded that self-reports are valid for classifying overweight/obesity, particularly in younger adults. Likewise, Brunner Huber (2007) examined the validity of self-reported height and weight in women of reproductive age in Atlanta, Georgia. The women underestimated weight by 4.6 lbs and overestimated height by 0.1 inches, leading to an underestimated BMI of 0.8 kg/m^2 (Brunner Huber, 2007). Based on these results the authors concluded that self-reported height and weight provided an accurate measure of actual BMI. In 2011, in a sample of Korean adults, the validity of self-reported height and weight was examined (Lee et al., 2011). The researchers found that height was slightly overestimated by 0.41 cm and weight by 0.12 kg, but ultimately self-reported and measured values were highly correlated. The authors concluded that self-reported height and weight should be used with caution, but can be useful when resources are limited in community health settings (Lee et al., 2011).

A systematic review was conducted of studies examining self-reported height and weight compared to measured data in adults (Connor Gorber et al., 2007). They found weight and derived BMI were underestimated, while height was overestimated and that these trends varied between men and women. The authors found that the majority of reviewed studies were of poor quality since many were missing important information, such as mean differences, which created difficulties for pooling estimates. However, the authors of the review concluded that self-reported measures can be useful, but correction factors are necessary to improve the accuracy of information when direct measurement is not feasible (Connor Gorber et al., 2007).

Although there are numerous studies examining the validity of self-reported height, weight and derived BMI in the general population, their conclusions are inconsistent. In addition, researchers have not identified a level of difference between self-reported and measured data that should be considered small enough to be the same, or large enough to be considered different; in other words the level where a finding is considered clinically significant is unknown. The discrepancies in adults' self-reported height, weight and differences in study conclusions suggest that their results are not generalizable and should be further examined, particularly in special populations.

3.2.5 Participating in research: Persons with ID

Studies examining the validity of self-reported height and weight have focused on the general population, leaving a significant gap in the literature pertaining to persons with ID. One of the possible reasons for this lack of evidence may be that individuals with ID may not have the opportunity to report on their own health. Research shows that persons with ID often depend on their caregivers to help meet their needs (Bhaumik et al., 2008); they often answer questions on their behalf, including health related topics. The presence of a caregiver may prevent an individual with ID from taking the initiative to answer questions on their own, and they may simply rely or expect their caregivers to answer for them. The lack of opportunity or engagement in these settings may prevent persons with ID from learning about their health. In addition, without the opportunity to self-report, and talk to a health care individual about one's health, including height and weight, persons with ID may not be able to fully participate in their own lives. It is unknown if individuals with ID understand or comprehend what their height and weight is and the risks of overweight/obesity.

3.2.6 Conclusion

It is important to reduce the proportion of overweight/obesity in persons with ID. It is therefore imperative for individuals at risk of, or experiencing overweight/obesity to be at the forefront of their health, where they can learn about the consequences of overweight/obesity. However, we are unable to gauge if persons with ID understand the concept of height and weight until they are given more opportunities to report on their health and participate in research directly. Therefore, the objective of this study is to examine the accuracy of self-reported height, weight and derived BMI in adults with ID and determine the diagnostic performance (sensitivity, specificity, positivity predictive value, negative predictive value) of self-reported derived BMI for the identification of overweight/obesity; the secondary objective is to determine if severity level of ID influences the validity of self-reports.

3.3 Method

3.3.1 Study design & ethics

This study employed a cross-sectional research design. This design allowed height and weight to be self-reported and immediately measured, eliminating the risk for any potential height or weight changes that can occur over a time lapse. The design allowed the researcher to attend different locations with minimal equipment and collect a large amount of data from participants in a short period of time. This study design also eliminated the risk of dropouts inherent in cohort study designs, as information from each participant was collected on the same day as recruitment.

Ethical approval was received from the University of Ontario Institute of Technology Research Ethics Board (Appendix 1) and all participants provided informed consent prior to the beginning of the study (Appendices 4-6). Special Olympics Ontario approved this study and provided assistance in recruiting participants; for example, they provided dates of events and coaches' contact information (Appendix 2).

3.3.2 Recruitment

Special Olympics Ontario members were recruited to participate while attending several Special Olympics Ontario program events. A booth was set up at events organized by Special Olympics Ontario in the Greater Toronto Area. Special Olympics members (age 12 and above) were invited to participate; persons over 18 were able to provide their own consent, and individuals under 18 were required to provide assent, in addition to consent from a caregiver. All potential participants were provided with a summary information sheet and informed about the project's objectives, methodology and risks and benefits.

3.3.3 Participants

We restricted inclusion to Special Olympics Ontario members. Individuals in wheelchairs were excluded from participating as proper equipment was not available to accommodate them and individuals were also excluded if assent/consent was not provided. A total of 65 adolescents and adults in Special Olympics Ontario were recruited for the study and were measured. For the purpose of this study only self-reported height and weight from adults (n=40) were included for analysis, of which 17 were female and 23 were male. When the question process was complete, participants were led to the trained investigator who measured their height and weight.

3.3.4 Procedures

Questionnaire

A trained interviewer sat down with participants at each venue. Using a questionnaire (Appendix 9), participants were asked about their age, sex, ID etiology, their level of ID, current living situation, and height and weight; trained interviewers recorded answers. The level of ID was determined by using self or proxy-reported information based on characteristics explained by the Diagnostic and Statistical Manual for Mental Disorders (DSM-5) (American Psychiatric Association, 2013). The participants were asked to provide their height in centimetres or feet, and weight in pounds or kilograms. It was found that individuals with moderate ID often consulted their proxy before responding; these were considered self-reports, as this is something that may happen in daily life, and the final decision to report the values came from the individuals with ID. Self-reported height and weight were used to calculate BMI (kg/m^2). The World Health Organization (WHO) age and sex-specific cut-off points were used to categorize participants as underweight (<18.5), normal weight (18.5-24.9), and/or overweight/obese (≥25) (World Health Organization, 2000). When the questionnaire was completed, participants were led to the trained investigator who measured their height and weight.

Measurements- height and weight

A standardized procedure (Canadian Society for Exercise Physiology: Physical Activity, Fitness & Lifestyle (CSEP-PATH)) was adopted to measure height and weight (Canadian Society for Exercise Physiology, 2013). A trained investigator measured and recorded height to the nearest 0.1 cm with a rigid stadiometer, with the participant standing without shoes, feet together, and head facing forward. Weight was measured with the participant wearing no shoes, in light clothing (shorts and t-shirt), and using a digital scale, recorded to the nearest 0.1 kg (Canadian Society for Exercise Physiology, 2013). BMI was calculated and the classification was recorded.

3.3.5 Statistical analysis

Distribution of the data was examined. Normality was assessed by computing the mean, median, skewness and kurtosis of self-reported and measured height, weight and calculated BMI.

Part 1: Characteristics of the sample and participants

Descriptive statistics were determined for all variables at the baseline assessment for all participants. Self-reported and measured height and weight were used to calculate BMI and weight categories. Throughout this paper, overweight and obesity categories were combined and in this manuscript will henceforth be referred to as overweight/obesity. This is commonly done in past research for the general population

(Brettschneider et al., 2012; Fonseca et al., 2009; Huybrechts et al., 2011; Kuczmarski et al., 2001) and if separated would have created groups that were too small.

Part 2: Agreement between self-reported and measured weight, height and derived BMI

To guide and perform appropriate statistical methods, a detailed, systematic study from the general population was consulted (De Vriendt et al., 2009). Differences between measured and reported height and weight were computed for females, males and for the total population. Paired samples t-tests were computed to determine if the measured and self-reported means in height, weight and BMI were different (a difference associated with a $p<0.05$ was deemed statistically significant). Effect size was calculated using Cohen's d (difference between the means divided by the standard deviation), a measure of the magnitude of the differences in measured and reported data, for both males and females and for the total sample population. A Cohen's d value of 0.2 represents a small effect size, 0.5 medium effect size, and 0.8 and above represents a large effect size (Cohen, 1992). This study calculated intra-class correlations coefficients which is consistent with the approach used by De Vriendt et al. (2009) and recommended by McGraw (McGraw & Wong, 1996). The intra-class correlation coefficient was calculated to determine the level of association for the measured and reported data. A correlation value of 0 indicates no relationship between the two variables, a value between 0.10 to 0.29 represents a small correlation, 0.30 to 0.49 a medium correlation, and 0.50 to 1.0 represents a strong correlation (Pallant, 2013).

Bland and Altman Plots were generated to examine how reported versus measured height, weight and derived BMI data differed. The difference score of measured and reported data was reported on the x axis, and the measured and reported mean were reported on the y axis. Bland and Altman Plots were also used as a visual aid to determine if any outliers existed in the data (Appendices 11-13).

Individuals with ID may provide self-reported values that are imprecise and considered outliers, (e.g. an individual may report that they were 500 lbs and genuinely believed that was their weight, when they were actually 120 lbs). The Outlier Labeling Rule and SPSS were used to determine if outliers existed in the data (Hoaglin & Iglewicz, 1987); the difference between the first and third quartile of the distribution was found and was multiplied by parameter *g*, (g= 2.2). The resulting value was added to the third quartile and subtracted from the first quartile to define boundaries; any values outside of the boundaries were considered outliers. Any reports that were outliers were removed and tests were repeated to determine if they influenced the results. All tests include the outlier unless otherwise specified.

Part 3: Impact of self-reported height and weight on classification in BMI-categories

In order to measure agreement between self-reported and measured BMI categories, an analysis was done to compare counts of individuals in each weight category. The difference in proportion of each weight category was assessed, as well as the 95% confidence interval (CI), using the Agresti method for comparing dependent proportions (Agresti & Finlay, 1997). McNemar's tests were performed for each BMI-category to determine if there were significant differences between self-reported and measured BMI proportion.

Sensitivity and specificity of the reported overweight/obesity BMI categories were calculated using the BMI derived from measured variables as the standard.

As well, the proportion of adults who were classified in a BMI category by self-reporting accurately (positive predictive value) and the proportion of individuals who were classified incorrectly using self-reported data (negative predictive value) were calculated. The kappa (κ) statistic which is a tool used to assess agreement beyond chance (Pallant, 2013), was used to determine the agreement between self-reported BMI categories and the measured BMI categories. Kappa values range from -1.00 suggesting disagreement and 1.00 representing agreement between values; values below 0.20 suggest poor agreement between two values, values between 0.61 and 0.80 represent good agreement and 0.8 and above represent very good agreement (Hulley, Cummings, Browner, Grady, & Newman, 2007).

Part 4: Agreement and impact of self-report derived BMI based on level of ID

The following tests were computed to examine the validity based on level of severity of ID (mild and moderate):

- An outlier calculation
- Agreement between measured and self-reported height, weight and derived BMI
- Impact of self-reported height and weight on classification in BMI-categories
- Overweight/obesity sensitivity and specificity analysis

Sensitivity and specificity were not performed for individuals with moderate ID due to the small sample size.

3.4 Results

Part 1: Characteristics of the sample and participants

Participants self-reported height and weight, and their descriptive information are included in table 1 (n= 40). The majority of participants (47.5%, n=19) were between the ages of 20 and 29, of which 87.5% (n=35) self-reported mild ID. Over half (n=23) of the participants lived at home with their family, and nearly 30.0% (n=11) lived independently. Based on self-reported height and weight, 72.5% (n=29) of participants were overweight/obese. Compared to measured height and weight data, self-reporting slightly overestimated the proportion of overweight/obesity. Based on both self-reported and measured results, females were slightly more likely to be overweight or obese compared to males.

Table 1.

Descriptive information of study participants by sex including: age groups, BMI status, level and type of ID and living arrangement

	Males (n=23)		Females (n=17)		Total (n=40)	
	N	%	N	%	N	%
Age						
20-29	11	47.8	8	47.1	19	47.5
30-39	3	13.0	5	29.4	8	20.0
40-49	6	26.1	2	11.8	8	20.0
50-59	3	13.0	2	11.8	5	12.6
BMI status (based on measured height and weight)						
Underweight	n/a	n/a	2	11.8	2	5.0
Normal weight	7	30.4	3	17.6	10	25.0
Overweight/Obese	16	69.4	12	70.5	28	70.0
BMI status (based on self-reported height and weight)						
Underweight	1	4.3	2	11.8	3	7.5
Normal weight	6	26.1	2	11.8	8	27.5
Overweight/Obese	16	69.5	13	76.3	29	72.5
Reported level of intellectual disability						
Mild	20	87.0	15	88.2	35	87.5
Moderate	3	13.0	2	11.8	5	12.5
Living arrangement						
At family home	11	47.8	11	64.7	23	57.5
In group home	5	21.7	1	5.9	5	12.5
Independent	6	26.1	5	29.4	11	27.5
Other	1	4.3	n/a	n/a	1	2.5

Part 2: Agreement between self-reported and measured weight, height and derived BMI

The self-reported and measured height, weight and derived BMI data for all participants are presented in Table 2a. Based on the paired-t test, it was found that the differences between measured and self-reported height of 3.27 cm, weight of 4.39 kg and BMI of 1.66 kg/m^2, were not significantly different. The intra-class correlation for height, weight and BMI showed strong and medium relationships (ICC= 0.646, 0.596, 0.369), and the Cohen's d effect sizes were small (0.165, 0.153, 0.148).

Females overestimated their weight and their derived BMI more than males by 9.48 kg and 4.54 kg/m^2 respectively. However, no important differences in mean height were evident. The magnitude of difference (effect size) between females reported and measured height, weight and calculated BMI were found to be of medium effect for weight and derived BMI (0.287, 0.324) and height was of small effect (<0.000). Females' measured and reported height were highly correlated (ICC= 0.909) and their weight and derived BMI correlations indicated medium relationships (ICC= 0.387, 0.232).

Males tended to overestimate their height by 5.75 cm and weight by 0.64 kg, resulting in an underestimated BMI by 0.47 kg/m^2. In addition, men's weight and calculated BMI effect size (0.034, 0.065), indicate a small effect, and thus the differences between measured and reported values were not large. Males' reported weight and calculated BMI were highly correlated with measured values (ICC= 0.863, 0.576).

Examination of the data identified one outlier, a female, whose data was removed from results in table 2b (the participant reported their weight approximately 350 lbs above their measured weight). With the outlier removed we found females tended to underestimate their weight by 0.30 kg and provided information leading to a slightly overestimated calculated BMI. The difference in weight for females and its effect size decreased, indicating the difference was small and correlation increased; the same trend occurred for females' calculated BMI.

Overall, with the removal of the outlier, the total sample weight overestimation decreased, the total sample weight and derived BMI effect size decreased and weight and derived BMI correlations increased. Although the effect sizes were considered small before the removal of the outlier, they became much closer to 0.

Table 2 a)

Comparison of self-reported and measured weight, height and derived BMI for females, males and the total sample

	Measured Mean (SD), *Median*	Self-reported Mean (SD), *Median*	Difference in Mean: Mean (SD)	Difference in Mean: 95% CI[a]	p-value[b]	Cohen's d[c]	ICC[d]
Females (n= 17)							
Weight (kg)	73.6 (21.1), *71.6*	83.1 (41.7), *70.3*	-9.48 (40.7)	-30.4 - 11.5	0.352	0.287	0.387
Height (cm)	155.7 (10.6), *157.6*	155.7 (14.4), *157.5*	0.07 (7.28)	-3.66 - 3.82	0.966	<0.000	0.909
BMI(kg/m^2)	30.3 (7.58), *31.5*	34.8 (18.1), *33.2*	-4.54 (18.3)	-13.9 - 4.85	0.321	0.324	0.232
Males (n= 23)							
Weight (kg)	85.6 (19.8), *85.2*	86.3 (21.7), *86.2*	-0.64 (14.4)	-6.87 - 5.60	0.835	0.034	0.863
Height (cm)	173.0 (8.04), *172.8*	178.8 (29.5), *172.7*	-5.75 (27.4)	-17.6 - 6.07	0.324	0.268	0.330
BMI(kg/m^2)	28.5 (5.99), *27.5*	28.0 (8.99), *27.2*	0.47 (8.34)	-3.14 - 4.07	0.791	0.065	0.576
Total (n= 40)							
Weight (kg)	80.5 (20.9), *80.9*	84.9 (31.3), *81.7*	-4.39 (28.6)	-13.54 - 4.75	0.337	0.165	0.596
Height (cm)	165.7 (12.5), *166.0*	168.9 (26.6), *165.1*	-3.27 (21.3)	-10.1 - 3.53	0.336	0.153	0.646
BMI(kg/m^2)	29.3 (6.68), *28.6*	30.9 (13.8), *28.4*	-1.66 (13.5)	-5.98 - 2.66	0.441	0.148	0.369

[a] 95% CI: 95% confidence interval
[b] According to the paired-samples T test
[c] *Cohen's d* values calculated as effect size
[d] Intra-class correlation coefficient
* $p<0.05$

Table 2 b)

Comparison of self-reported and measured weight, height and derived BMI for females and the total sample without an outlier

	Measured Mean (SD), *Median*	Self-reported Mean (SD), *Median*	Difference in Mean: Mean (SD)	Difference in Mean: 95% CI[a]	p-value[b]	Cohens d[c]	ICC[d]
Females (n= 16)							
Weight (kg)	74.4 (21.5), *75.6*	74.1 (19.8), *69.4*	0.30 (6.10)	-2.95 - 3.54	0.848	0.015	0.978
Height (cm)	155.9 (10.9), *157.8*	155.9 (14.8), *158.8*	0.11 (7.51)	-3.89 - 4.11	0.956	<0.000	0.909
BMI(kg/m^2)	30.5 (7.76), *31.7*	30.9 (8.27), *31.6*	-0.37 (6.35)	-3.75 - 3.01	0.819	0.050	0.814
Total (n= 39)							
Weight (kg)	81.0 (20.9), *82.3*	81.3 (21.5), *81.7*	-0.25 (11.6)	-4.02 - 3.51	0.893	0.014	0.919
Height (cm)	166.0 (12.5), *166.3*	169.4 (26.8), *165.1*	-3.35 (21.5)	-10.3 - 3.63	0.338	0.163	0.639
BMI(kg/m^2)	29.3 (6.75), *28.8*	29.2 (8.70), *28.3*	0.12 (7.51)	-2.31 - 2.55	0.919	0.013	0.698

[a] 95% CI: 95% confidence interval
[b] According to the paired-samples T test
[c] *Cohen's d* values calculated as effect size
[d] Intra-class correlation coefficient
* $p<0.05$

Part 3: Impact of self-reported height and weight on classification in BMI-categories

The proportion of self-reported and measured BMI-categories of adult participants according to the WHO cut-off criteria are presented in Table 3. For females, males and the total population, each category's confidence interval included 0, thus there was no statistically significant difference in BMI category proportion obtained using self-reported versus measured approaches. Normal weight proportion was underestimated, while overweight/obesity proportion was overestimated for females and the total sample. Results were repeated with an outlier removed and were virtually the same (Appendix 14).

Table 3.

Self-reported and measured proportion of adults with ID in different BMI categories according to the World Health Organization (WHO) cutoffs

	Measured		Self-reported		Difference[a]		p^b
	%	(n)	%	(n)	%	95% CI	
Females (n=17)							
Underweight	11.8	2	11.8	2	0		1.00
Normal weight	17.6	3	11.8	2	5.8	-5.3 - 17.1	1.00
Overweight/Obese	70.6	12	76.4	13	-5.8	-17.1 - 5.3	1.00
Males (n=23)							
Underweight	0	0	4.3	1	-4.3	-12.7 - 3.98	-
Normal weight	30.4	7	26.1	6	4.3	-10.3 - 19.0	1.00
Overweight/Obese	69.6	16	69.6	16	0	-17.0 - 17.0	1.00
Total (n=40)							
Underweight	5.0	2	7.5	3	-2.5	-7.34 - 2.34	1.00
Normal weight	25.0	10	20.0	8	5.0	-4.68 - 14.7	0.63
Overweight/Obese	70.0	28	72.5	29	-2.5	-13.4 - 8.43	1.00

Note. A blank space indicates that the data could not be calculated
[a] Difference in proportion of underweight, normal weight, overweight/obesity were obtained using the Agresti method for comparing dependent proportions
[b]According to McNemar's test

Table 4 shows the number and percentages of adults classified in the correct and adjacent BMI-category according to their self-report derived BMI and their measured BMI. It was found that only 5.9% of females (n=1) was misclassified in an adjacent category and 16 (94.4%) were classified in the correct BMI category. Males self-reported 82.4% (n=19) in the correct BMI category, and 17.3% (n=4) were misclassified. In the total sample, it was found that 87.5% (n=35) adults were classified in the correct BMI category, 10.0% (n=4) of adults were classified in the adjacent category and 2.5% (n=1) of individuals of the sample was grossly misclassified (i.e. by 2 categories). Of these misclassifications, 7.5% (n=3) of adults were reported as overweight/obese but were actually classified as normal weight by measured data. Five percent (n=2) of individuals who were classified as overweight/obese by measured data, reported otherwise.

Table 4.

The number and proportion of adults with ID classified in different BMI categories based on self-reported and measured height and weight

		BMI-category based on Measured BMI						Total	
		Underweight n (%)		Normal weight n (%)		Overweight/obese n (%)		n	(%)
BMI-category based on self-reported BMI	Females (n=17)								
	Underweight	2	11.8	0	0.0	0	0.0	2	11.8
	Normal weight	0	0.0	2	11.8	0	0.0	2	11.8
	Overweight/ obese	0	0.0	1	5.9	12	70.8	13	76.7
	Total	2	11.8	3	17.6	12	70.8	17	100
BMI-category based on self-reported BMI	Males (n=23)								
	Underweight	0	0.0	0	0.0	1	4.3	1	4.3
	Normal weight	0	0.0	5	21.7	1	4.3	6	26.1
	Overweight/ Obese	0	0.0	2	8.7	14	60.7	16	69.4
	Total	0	0.0	7	30.3	16	73.6	23	100
BMI-category based on self-reported BMI	Total (n=40)								
	Underweight	2	5.0	0	0.0	1	2.5	3	7.5
	Normal weight	0	0.0	7	17.5	1	2.5	8	20.0
	Overweight/ Obese	0	0.0	3	7.5	26	65.0	29	72.5
	Total	2	5.0	10	25.0	28	70.0	40	100

Values in highlighted boxes represent accurate classification by self-report

Table 5 summarizes the sensitivity and specificity results for self-reported height and weight to determine overweight/obesity in females, males and the total sample. Females' sensitivity for overweight/obesity was 100.0 and specificity was 80.0%, and the kappa statistic was 0.890, very close to 1. For males, sensitivity was 87.5%, specificity 71.4% and the kappa statistic was 0.589. The sensitivity value for the total sample for overweight/obesity was 92.9%, and specificity was 75.0%. The positive predictive value (PPV) for overweight/obesity indicated that 89.7% of participants who reported as overweight/obese were truly overweight/obese. The negative predictive value (NPV) showed that 81.8% of the participants who reported as not being overweight/obese truly were not overweight/obese. The kappa value (0.695) indicated a medium level of agreement for the classification of overweight/obesity based on self-report derived BMI. With the outliers removed, sensitivity, specificity, PPV, NPV and kappa statistic were very similar (Appendix 16).

Table 5.

Diagnostic performance of self-reported height and weight for determining overweight/obesity in adults with ID

	Sensitivity		Specificity		PPV[a]		NPV[b]		Kappa statistic
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%
Females (n=17)									
BMI Category Overweight/ Obese	100.0	69.9 - 100.0	80.0	29.9 - 98.9	92.3	62.1 - 99.6	100.0	4.0 - 37.9	0.850
Male (n=23)									
BMI Category Overweight/ Obese	87.5	60.4 - 97.8	71.4	30.3 - 94.9	87.5	60.4 - 97.8	71.4	30.3 - 94.9	0.589
Total (n=40)									
BMI Category Overweight/ Obese	92.9	75.0 - 98.8	75.0	42.8 - 93.3	89.7	71.5 - 97.3	81.8	47.8 - 96.8	0.695

[a] Positive Predictive Value, [b] Negative Predictive Value

Part 4 a): Agreement and impact of self-report derived BMI based on level of ID

The analysis of self-reported and measured height, weight and calculated BMI was stratified according to self-reported level of ID (Table 6a). In both mild and moderate ID categories the differences between measured and self-reported height, weight and derived BMI were not statistically significant, with all p-values much larger than 0.05.

Individuals with mild ID overestimated height, weight and calculated BMI (difference of 4.00 cm, 5.26 kg, 1.98 kg/m^2); the differences were not statistically significant, the measured and reported height, weight and derived BMI values were moderately correlated (ICC= 0.559, 0.548, 0.349) and the effect sizes were small (0.180, 0.194, 0.174). The individuals with moderate ID tended to underestimate their weight resulting in an underestimation of their BMI (Table 6a). The effect sizes for height and weight and derived BMI for the moderate ID group were also small (0.009, 0.081, 0.057), and the correlation values were close to 1 (ICC= 0.991, 0.986, 0.931), indicating a strong relationship between the measured and reported values.

A sensitivity analysis with the exclusion of the outlier was conducted (Table 6b). With the removal of the outlier, it was found that the mild ID group's differences decreased for weight, and derived BMI (-0.54 kg, -0.06 kg/m^2). The effect sizes for weight and derived BMI also decreased (0.028, 0.012) and the correlations increased (ICC= 0.908, 0.683). In addition, without the outlier, individuals with mild ID appeared to report better overall, than individuals with moderate ID.

Table 6 a)

Proportion of adults with ID in different BMI categories according to source of data (self-reported vs. measured height and weight), the World Health Organization (WHO) cutoffs and severity level of ID

	Measured Mean (SD), *Median*	Self-reported Mean (SD), *Median*	Difference in Mean: Mean (SD)	Difference in Mean: 95% CI[a]	p-value [b]	Cohen's d[c]	ICC[d]
Mild (n= 35)							
Weight (kg)	81.4 (21.2), *82.3*	86.7 (32.4), *81.6*	-5.26 (30.5)	-15.7 - 5.21	0.314	0.194	0.548
Height (m)	166.7 (10.9), *167.8*	170.4 (26.9), *165.1*	-3.71 (22.7)	-11.5 - 4.08	0.340	0.180	0.559
BMI(kg/m^2)	29.2 (6.94), *27.7*	31.2 (14.7), *28.3*	-1.98 (14.4)	-6.93 - 2.97	0.422	0.174	0.349
Moderate (n= 5)							
Weight (kg)	74.4 (20.8), *68.9*	72.7 (21.3), *68.5*	1.71 (3.58)	-2.74 - 6.15	0.347	0.081	0.986
Height (m)	158.3 (21.2), *158.4*	158.5 (24.5), *162.6*	-0.22 (4.38)	-5.65 - 5.21	0.916	0.009	0.991
BMI(kg/m^2)	29.6 (5.06), *28.9*	29.9 (5.52), *28.6*	0.57 (2.70)	-2.78 - 3.92	0.662	0.057	0.931

[a] 95% CI: 95% confidence interval
[b] According to the paired-samples T test
[c] *Cohen's d* values calculated as effect size
[d] Intra-class correlation coefficient
* $p<0.05$

Table 6 b)

Proportion of adults with ID in different BMI categories according to source of data (self vs. measured height and weight), the World Health Organization (WHO) cutoffs and severity level of ID without outlier

	Measured	Self-reported	Difference in Mean		p-	Cohen's	ICC[d]
	Mean (SD), *Median*	Mean (SD), *Median*	Mean (SD)	95% CI[a]	value [b]	d[c]	
Mild (n= 34)							
Weight (kg)	81.9 (21.2), 83.7	82.5 (21.6), *81.7*	-0.54 (12.4)	-4.86 - 3.78	0.801	0.028	0.908
Height (m)	167.2 (10.7), *168.4*	170.9 (27.1), *165.1*	-3.81 (23.0)	-11.8 - 4.22	0.342	0.180	0.547
BMI(kg/m^2)	29.3 (7.03), *27.9*	29.2 (9.14), *27.9*	-0.06 (7.99)	-2.73 - 2.84	0.967	0.012	0.683

[a] 95% CI: 95% confidence interval
[b] According to the paired-samples T test
[c] *Cohen's d* values calculated as effect size
[d] Intra-class correlation coefficient
* p<0.05

Part 4 b): Agreement and impact of self-report derived BMI based on level of ID

The proportion of self-reported and measured BMI-categories of adults with mild and moderate ID according to the WHO cut-off criteria are presented in Table 7. The proportion of overweight/obesity was overestimated in individuals with mild ID, whereas the proportion of individuals with normal weight was underestimated. McNemars' test found that the difference in proportion's for all weight categories were not statistically significant. Individuals with moderate ID were all classified in the correct BMI category. The results for mild ID were repeated with an outlier removed and were very similar (Appendix 17).

Table 7.

Categorizations of adults with Mild ID and Moderate ID in different BMI categories according to the World Health Organization (WHO) cutoffs, and differences between self-reported and measured proportion in each category

	Measured		Self-reported		Difference[a]		P^b
	%	(n)	%	(n)	%	95% CI	
Mild ID reports (n=35)							
Underweight	5.7	2	8.6	3	-2.9	-8.38 - 2.66	1.00
Normal weight	25.7	9	20	7	5.7	-5.32 - 16.8	0.63
Overweight/Obese	68.6	24	71.4	25	-2.8	-15.3 - 9.63	1.00
Moderate ID reports (n=5)							
Underweight							
Normal weight	20	1	20	1	0		1.00
Overweight/Obese	80	4	80	4	0		1.00

Note. A blank space indicates that the data could not be calculated
[a] Difference in proportion of underweight, normal weight, overweight and obesity were obtained using the Agresti method for comparing dependent proportions
[b]According to McNemar's test

Table 8 summarizes the accuracy of overweight/obesity determined through self-reports in adults with mild ID compared with the BMI computed from the measured variables. The sensitivity value of overweight/obesity was 91.7%, and the specificity was 72.7%. The PPV was 88% and the NPV was 80.0%. The kappa value (0.660) indicates a medium level of agreement for the classification of overweight/obesity based on self-report derived BMI in persons with mild ID. With the outlier removed, sensitivity, specificity, PPV, NPV and kappa statistic were very similar (Appendix 18). This calculation could not be repeated for those with moderate ID due to small numbers.

Table 8.

Diagnostic performance of self-reported height and weight for determining overweight/obesity in adults with Mild ID (n=35)

	Sensitivity		Specificity		PPV[a]		NPV[b]		Kappa statistic
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%
BMI category									
Overweight/ Obese	91.7	71.5 - 98.5	72.7	39.3 - 92.7	88.0	67.7 - 96.8	80.0	44.2 - 96.5	0.660

[a] Positive Predictive Value, [b] Negative Predictive Value

3.5 Discussion

3.5.1 Summary of findings

The objective of this study was to investigate the accuracy of self-reported height, weight and derived BMI in Special Olympics participants. Our results indicate that self-reported and measured height and weight were not significantly different from measured height and weight data. It was found that males had more accurate weight and derived BMI compared to females, but women had higher sensitivity and specificity for overweight/obesity proportion. When an outlier was removed, the differences in reported and measured data decreased, remained not statistically significant, and misclassification and sensitivity and specificity results remained very similar. The lack of statistical significance with and without an outlier may be due to the small sample size. Overall, it was found that reported height and weight lead to an overestimation of overweight/obesity compared to measured results.

The second objective of this study was to investigate whether severity level of ID was associated with differences in the validity of self-reported height and weight for BMI. The results show that in individuals with mild ID, like in the full sample, the proportion of overweight/obesity individuals was overestimated. When an outlier was removed from calculations for the mild ID group, weight and calculated BMI differences were smaller and closer to 0 than individuals with moderate ID. Overall, the data indicates that the total group of individuals with ID were quite accurate at reporting their own height and weight, thus justifying further study with a larger sample.

3.5.2 Interpretation of findings in light of previous research

Part 1: Characteristics of the sample and participants

In this study, 40 individuals provided their height and weight. Compared to research from the general population, this sample population was very small. Studies in the general population had very large sample sizes: the smallest included close to 340 (Brunner Huber, 2007) and others much greater than 1000 (Elgar & Stewart, 2008; John et al., 2005; Kuczmarski et al., 2001; Lee et al., 2011). As this was the first study conducted with individuals with ID, a very large sample size was not desired nor was it feasible. Over half of our sample was male (57.5%, n=23) and the remaining were females. Unlike our sample of individuals with ID that self-reported, the general population tended to have slightly more women than men report height and weight (Elgar & Stewart, 2008; Kuczmarski et al., 2001; Lee et al., 2011). Our sample is more similar to studies which include individuals with ID, such as Foley et al. (2012), which found that in a sample of Special Olympians with ID, 57.0% of the population was male and, as research states, the proportion of ID is higher in males compared to females (Maulik et al., 2011).

Part 2: Agreement between self-reported and measured weight, height and derived BMI

The current study compared self-reported and measured height, weight and derived BMI among a sample of males and females with ID. Many of our findings were similar to those found in the general population. Without the outlier, we found that the total mean sample height was overestimated by 3.35 cm. This result for is similar to studies cited in a systematic review which found that height in 53 studies was most often overestimated and the differences ranged across studies from 0.2 cm to 7.5 cm (Connor Gorber et al., 2007). The current study found that females without the outlier underestimated their weight (0.30 kg) and males overestimated their weight (0.64 kg). Results were similar to the 56 studies in the systematic review, where women underestimated weight; however, in contrast to our results, the review found that males mostly underestimated weight (Connor Gorber et al., 2007). Our study found that without the outlier, derived BMI was underestimated in the total sample and in males. However, without the outlier, derived BMI was overestimated among females. Conversely, in the general population it is found that both males and females tend to underestimate their calculated BMI's (Brunner Huber, 2007; Connor Gorber et al., 2007; Elgar & Stewart, 2008; John et al., 2005; Kuczmarski et al., 2001; Lee et al., 2011). The difference between results in females with ID versus the general population needs to be investigated further. The results in this study found that all calculated differences were not significantly different. In contrast, Brunner Huber (2007), Elgar et al. (2008), and Lee et al. (2010) all reported significant differences between measured and reported height, weight and derived BMI.

This study reports on the magnitude of the difference between measured and reported height, weight and derived BMI, known as effect size (Cohen's d). We found that Cohen's d values, were low for all calculated differences. For the total population, height, weight and derived BMI effect size values were below 0.2, indicating the magnitude of the differences were minor. The majority of other studies examining the validity of self-reported height and weight in adults did not report effect size. Correlations between measured and self-reported height, weight and calculated BMI, were high (0.698 to 0.919), and comparable with results from previous studies (Elgar & Stewart, 2008; Kuczmarski et al., 2001; Lee et al., 2011). However, these high correlations do not suggest self-reports are truly valid; it has been reported that high correlations do not imply good agreement between two measurements, and therefore, should not be exclusively used to suggest one measurement technique is equivalent or superior to another (Bland & Altman, 2010).

Part 3: Impact of self-reported height and weight on classification in BMI-categories

This study found that self-reported data led to an overestimate of the proportion of overweight/obesity compared to measured values; the general population, in contrast, tends to underestimate the proportion of overweight/obesity (Elgar & Stewart, 2008; John et al., 2005; Kuczmarski et al., 2001; Lee et al., 2011). Results from females in our sample influence this result since they were more likely than males to report height and weight, which lead to an overestimate of BMI and overweight/obesity. Although this result needs to be confirmed with a larger sample, some studies have suggested that people with ID perceive body image differently, either under or overestimating the correct BMI range (Ayaso-Maneiro, Domínguez-Prado, & García-Soidan, 2014). This study also found that through self-reports, 87.5% of the population were classified in the correct weight category, and 12.5% were classified in the incorrect category. Two individuals (5.0%) were classified as overweight/obese based on the measured variables, but were classified otherwise based on the self-reported variables, and thus would be missed for an intervention directed towards individuals who are overweight/obese. Similarly, in the general population, it was found that in a sample of women, 84.0% were classified in the correct BMI category using self-reported height and weight (Brunner Huber, 2007). It has been reported that the validity of a screen (self-reported height and weight) is poor when it is not able to detect a large amount of overweight/obese cases, (Elgar, Roberts, Tudor-Smith, & Moore, 2005). Elgar et al. (2008), found consistency between studies and reported that self-reported screening leads to the misclassification of approximately 1 in 3 cases of obesity (Elgar et al., 2005; Wang, Patterson, & Hills, 2002); whereas the current study found only 1 in 14 cases of overweight/obesity were misclassified. Since our study did not miss a significant amount of overweight/obesity cases, we considered the self-reported height and weight for overweight/obesity data valid.

This study also found that self-reported height, weight and derived BMI for the identification of overweight/obesity in the total sample had a sensitivity of 92.9% and a specificity of 75.0%. As well, PPV was 89.7% and NPV was 81.8%, and the kappa statistic (0.695) indicated relatively good agreement between overweight/obesity classification from self-reported and measured values. In the general population, two studies were found that had high sensitivity, but specificity was slightly higher; these studies considered the use of self-reports as valid alternatives of direct measurements

(Lee et al., 2011), specifically in younger adults (Kuczmarski et al., 2001). Kuczmarski et al. (2001), suggests that poor sensitivity is not desired for obesity studies and we agree. Lower sensitivity means many false negatives, therefore an individual may be overweight/obese but go undetected, but with high sensitivity individuals who truly need overweight/obesity interventions would not be missed. Incorrectly stating that someone is overweight/obese when they are truly of normal BMI (the result of low specificity) is less problematic since giving guidance on good nutrition and exercise to both healthy and unhealthy individuals is useful. Thus, in our opinion higher sensitivity is preferable to high specificity for these types of studies. This is especially true for individuals with ID, where the health risks of overweight/obesity are extremely high and thus any need for interventions is priority.

Part 4: Agreement and impact of self-report derived BMI based on level of ID

We found that individuals with mild ID without the outlier, were better at reporting weight and derived BMI, compared to individuals with moderate ID. Reports from people with mild ID results in underestimated weight (0.54 kg) and BMI (0.06 kg/m^2), whereas results from people with moderate ID, showed overestimates (1.71 kg and 0.57 kg/m^2).

The level of misclassification in persons with mild ID looked similar to the total sample results, and individuals with moderate ID categorized all individuals correctly. Although self-reported weight and derived BMI values without the outlier were more accurate than values from those with moderate ID, the results from the individuals with moderate ID were still closer than we would have expected. This is likely because they often consulted their caregivers before responding. Additionally, it has been reported that both individuals with mild and moderate severity levels of ID appear capable of self-reporting health, but the accuracy of reports depends on the level of detail needed and other factors such as the context of request (Finlay & Lyons, 2001).

Sensitivity and specificity remained high when persons with mild ID were examined alone. The confidence interval for specificity was notably large, indicating the need for stronger power in the study. The general population tends to report higher specificities versus sensitivities (Kuczmarski et al., 2001; Lee et al., 2011); thus our study provides new information on a population where the reverse is seen.

3.5.3 Strengths and limitations

To the best of our knowledge, this is the first study to examine the accuracy of self-reported height and weight in persons with ID. A second strength of this study is that the data collection simulated a real life setting. Participants were given the opportunity to report on their own without the influence of a caregiver, but if needed, participants were given the option of consulting with a caregiver. This often took place with individuals with moderate ID and may explain why their reports were very accurate. This approach to data collection resembles a realistic scenario, where persons with ID are often with their caregiver during health care appointments, providing them the opportunity to consult with them before answering any health questions. This is consistent with results from Lunsky et al. (2002), which concluded that the utilization of health reports from persons with mild ID is best when using both self-reports and staff reports. A third strength of this study is that we asked participants to verbally report their height and weight for BMI, rather than using a written questionnaire. It has been reported that avoiding certain data collection techniques, such as Likert scales, negative wording, and the use of modifiers, researchers can improve self-reports of individuals with ID (Fujiura, 2012). This study allowed the trained investigators to explain each question, which gave the participants the opportunity to fully understand.

A fourth strength of this study is the inclusion of individuals with moderate ID. Our study found that individuals with moderate ID can be included in health research; they are more likely than those with mild ID to seek caregiver input, which contributes to accurate self-reports. A fifth strength is that this study immediately measured height and weight after self-reporting, eliminating the risk of bias from collecting data from participants whose weight may change over time. In addition, height and weight were measured in a standardized way. The sixth strength of this study is its thorough reporting. In general, the level to which self-reported height and weight for BMI should be accepted or rejected has not been established. Therefore, as suggested by Connor Gorber et al. (2007), this area of research can be enhanced by improving the quality of reporting, by consistently reporting indices of agreement including: mean, minimum and maximum differences, standard deviations of differences, and errors of measurement. This study reports these indices of agreements, and therefore, separates itself from many studies in the general population. Lastly, this study reported the use of an outlier calculation, which many other studies fail to address.

As with all studies, there are limitations to our findings. The biggest limitation is the small sample size; evidence of low numbers can be seen in the wide confidence intervals. In addition for some results, even when large mean differences were found, they were not found to be statistically significant, compared to previous literature which occasionally found smaller differences that were statistically significant. However, the fact that we did not find significant differences is encouraging in regards to the validity of self-reported height and weight in adults with ID. Another limitation is the low numbers of individuals with moderate ID. Although mild ID is more common than other levels of severity, having a larger number of individuals with moderate ID would have made it possible to report with more confidence on their responses. In addition, the low numbers meant that sub-analysis among people with moderate ID were sometimes not possible.

This study also found that the standard deviations of the differences for height, weight and derived BMI were large. It is reported that large standard deviations in the mean difference of measured and reported height and weight can considerably alter BMI classification and cause under or overestimated proportion of overweight/obesity (Connor Gorber et al., 2007). Although the standard deviations in this study indicate there was individual variability in self-reports, only a few individuals were placed in incorrect BMI categories, and thus BMI classifications were not considerably under or overestimated. Another limitation stems from our study population of Special Olympics participants. Although most individuals who participate in Special Olympics are not elite athletes, they do participate in athletics and, therefore, engage in activity more often than their peers who are not enrolled. Consequently, it is possible that our sample is not representative of all those with ID. Lastly, the level of ID obtained from the original questionnaire was not measured with a trained professional or using standardized tests; it was obtained using self or proxy-reported information based on characteristics explained by the DSM-5 (American Psychiatric Association, 2013). Therefore, the proportion of the different ID levels may not represent a true distribution of all adults with ID. It is recommended that future studies measure the level of ID, and obtain the diagnosed ID etiology.

Despite limitations, we did find that persons with ID were fairly accurate at reporting their own height and weight information. These results are promising, but larger studies need to be conducted. Larger studies can confirm that persons with ID accurately report their own height and weight, and when measuring is not available, we can rely on their reports to collect data on BMI categories.

3.5.4 Implications and future research

Persons with ID are often not included or asked questions about their health, as it is believed their disabilities influence the validity of their reports. For the same reason, their reports are often not used in health research. This study allows individuals with ID to self-report, an experience that contributes to empowerment, self-determination and choice: three principles in the contemporary approach to the health of individuals with ID (Fujiura, 2012). Compared to the general population, the results of this study suggest that adults with ID are relatively accurate at reporting their own height and weight. This suggests that self-reports for overweight/obesity data in persons with ID may be valid enough to use. However, the proportion of overweight/obesity is a serious issue that persons with ID often face and should not be taken lightly. The gold standard of physical measurement remains the best option in obtaining height and weight data, but when this is not feasible, our results suggest that health researchers and/or health practitioners should include persons with ID and rely on their self-reported height and weight.

This study found that over half of the participants were overweight/obese, which is consistent with previous literature. Upon data collection it was observed that many participants understood the risks of overweight/obesity and were often interested in monitoring their weight. By collecting height and weight information and providing the reasoning behind this study to participants, this study brought more awareness to the risks of overweight/obesity. Future studies may further examine the risks of overweight/obesity in persons with ID by asking about their height and weight, and incorporate questions regarding their perceived body image, and health habits.

3.5.5 Clinical and Public Health Significance

None of the results from this study that compared self-reported to measured, height, weight, and derived BMI (see part 2 results) were statistically significant. The question becomes whether the differences are clinically significant; however, there are no recommendations available to guide researchers and clinicians regarding what should be considered clinically meaningful. No prior studies identify what should be considered a minimal clinically important difference between self and measured height, weight, and derived BMI. Indeed, the review by Connor Gorber et al. (2007), found that variability in results from included studies was high and "no overall effect size could be estimated". Nevertheless, the results from the current study on the diagnostic performance of self-reported height and weight for determining overweight/obesity (see part 3 results) provide insight on its clinical and public health significance. As mentioned (see part 3 results) the high sensitivity generated by self-reports translated to approximately only 1 in 14 people with overweight/obesity being misclassified.

In a clinical situation, although direct measurement remains the best option, based on this study's findings, health care providers can feel confident that individuals with mild ID can provide accurate height and weight values and can include them in the clinical decision making process. For example, during a dietitian appointment, if individuals with ID report their height and weight, only 7% of individuals would be missed for a healthy eating intervention. And from a public health perspective, researchers can collect self-reported height and weight data from a large sample of individual with ID and be confident that only a small proportion of cases would be missed. Therefore, public health researchers and administrators can accurately guide programs and interventions directed at reducing overweight/obesity in persons with ID.

3.5.6 Conclusion

The objective of this study was to determine the accuracy of self-reported height and weight in a sample of Special Olympics participants. Our results indicate that adults with ID were accurate at reporting their own height and weight, and the results were similar to those from studies for the general population that also recommended the use of self-reports. We also found that persons with ID tended to overestimate the proportion of overweight/obesity which is different than the general population who tend to underesimate the proportion of overweight/obesity. Utlimately, this study found a small percentage of BMI categories were misclassified, which led to a high sensitivity when using self-reports to identify overweight/obesity.

This study confirms that persons with ID are accurate at reporting their own height and weight. To the degree possible, they should be given the opportunity to be included in health care decisions. If the gold standard of physical measurement is not feasible, it is an option to use self-reported height and weight in persons with ID. This study was the first of its kind, therefore, further research with a larger and more representative sample of all persons with ID is warranted.

4 MANUSCRIPT 2

4.1 Abstract

Overweight/obesity are common in adults with intellectual disabilities (ID) which has a poor influence on their health. To meet their health needs individuals with ID frequently rely on parents or other caregivers (i.e. proxies) to answer questions on their behalf. Such questions include height and weight, which are used to calculate body mass index (BMI). In the general population, the use of proxy-reported height and weight to compute BMI has been validated. However, the validity of proxy-responses to compute BMI has not been validated among adults with ID. The primary objective of this study was to determine the accuracy of proxy-reported height, weight and derived BMI among adults with ID and determine the diagnostic performance of proxy-report derived BMI for the identification of overweight/obesity. A secondary objective was to determine the validity of reports based on the type of proxy, such as parents and other types of caregivers. A total of 21 caregivers and parents were asked to report height and weight on behalf of adults with ID in their care, which were compared to measured height and weight. Proxy reports were collected at Special Olympics Ontario events and the height and weight of individuals with ID were measured with standardized equipment and procedures. Results suggest that, on average, proxy-respondents overestimated height by 2.70 cm and underestimated weight by 0.837 kg. This results in an underestimation of the BMI by 1.19 kg/m^2. The sensitivity and specificity of BMI based on proxy-report measures were 84.6% and 75.0% respectively. The study found that parent proxies were overall better at reporting height and weight compared to caregiver proxies. Overall, proxy-reports may be useful when direct measurements are not available, but as a result

of large confidence intervals due to small sample size, further research in this field with larger samples is warranted.

4.2 Introduction

4.2.1 Intellectual disability

Intellectual disability (ID) affects approximately 1% of the total population (Maulik et al., 2011). Individuals with ID are characterized by limitations in intellectual functioning, they also experience problems with communication and restrictions in everyday social and practical skills (American Association on Intellectual and Developmental Disabilities, 2013). The World Health Organization International Classification of Diseases (WHO-ICF) adds that individuals with disabilities, such as ID, are a group of people that frequently need support to maximize their activity and participation in daily endeavors, but are not defined by their disability (World Health Organization, 2001b). Individuals with ID not only experience difficulties in intellectual functioning and behavior, they also experience many health problems, including an array of chronic diseases (Lunsky et al., 2013). Overweight/obesity is one specific health condition that individuals with ID often experience and it is a risk factor for other chronic illnesses which contribute to their complex health needs.

The combination of limitations in intellectual functioning and communication, chronic diseases, and unmet health needs influences the ability of persons with ID to live independently and be healthy. Consequently, they may become reliant on their parents or caregivers for support (Bhaumik et al., 2008). Parents and caregivers of persons with ID become responsible for answering questions on their behalf (also referred to as a proxy) in an effort to help them meet their needs. For example, parents and caregivers may be responsible for answering questions regarding height and weight data used to calculate the prevalence of overweight/obesity. To date no literature exists examining accurate methods of reporting height and weight among those with ID.

4.2.2 Overweight/obesity in adults with ID

The prevalence of overweight/obesity in adults with ID around the world is concerning. In a sample of Americans who participate in Special Olympics, the obesity levels for adult males with ID across several age groups were between 38.0-45.0%, which was 5.0-10.0% higher than the general population (Foley et al., 2013). The prevalence of obesity was even higher among women with ID: research showed that 52.0-57.0% of adult females were obese, which was 20.0% higher than the general population (Foley et al., 2013). The high prevalence of overweight and obesity in persons with ID is consistently reported in other developed countries. In New Zealand, 51.0% of persons with ID were reported as obese, which was 21.0% higher than the general population (Stedman & Leland, 2010); in the Netherlands, 38.0% were overweight, or approximately 10.0% higher than the general population (de Winter et al., 2012). Overall, the prevalence of overweight and obesity in adults with ID has proven to be higher than the general population.

The high prevalence of overweight and obesity in adults with ID has been attributed to genetic disorders (Gravestock, 2000; Pogson, 2012), sex (Melville et al., 2007), severity of ID (Robertson, Emerson, Gregory, Hatton, Turner, et al., 2000), medication use (de Kuijper et al., 2010; Lunsky et al., 2013), physical inactivity levels (Salaun & Berthouze-Aranda, 2011; Temple et al., 2006), and unhealthy nutritional habits (Bandini et al., 2005; Pogson, 2012). Overall, the higher rates of overweight and obesity in adults with ID is a concern as they only add to the complexity of their health and need to be addressed.

4.2.3 Body mass index as a measure of body adiposity

There are many different methods used to assess body adiposity; one of the most accessible tools is body mass index (BMI). To obtain BMI, height and weight are obtained and represented in kg/m^2; it is used to classify individuals as underweight, normal weight, and overweight or obese (Morrissey et al., 2006; World Health Organization, 2000). It has been suggested that BMI may not be reliable as it may over or underestimate overweight/obesity (Walls et al., 2011) and because it does not take into consideration muscularity versus body fatness (Canadian Society for Exercise Physiology, 2013). However, the World Health Organization (WHO) has stated that it is a practical measure for large populations (World Health Organization, 2000).

The use of BMI to measure body fatness in individuals with ID has been validated by two studies. Two studies assessed body composition with a dual-energy X-ray absorptiometer (DXA) and results of variance in body fat using this instrument were compared to results determined with the BMI measure (Casey, 2013; Temple et al., 2010). Both studies confirmed that BMI accounted for a large percentage in total body fat (83%) in individuals with ID (Temple et al., 2010) and thus showed good agreement with the DXA (Casey, 2013; Temple et al., 2010).

4.2.4 Proxy-reporting for overweight/obesity prevalence

Overweight/obesity have proven to be serious health conditions that often affect the lives of adults with ID. To obtain overweight/obesity data in persons with ID, it is often not feasible to use the gold standard of physically measuring height and weight to calculate BMI as it is often time consuming and expensive (Connor Gorber et al., 2007). Therefore, height and weight data are often obtained using self-reports (Connor Gorber et al., 2007; George et al., 2011; Rimmer & Yamaki, 2006). But, as mentioned previously, individuals with ID often rely on their parents/caregivers for support (Bhaumik et al., 2008); for instance, parents/caregivers may take on the role of answering questions on their behalf. This technique is also used in the general population, where parents or caregivers provide height and weight information for their children or teenagers.

Several studies have examined the validity of proxy-reported height and weight in children and adolescents in the general population. These studies examined the difference in measured versus reported height, weight and calculated BMI; consistently studies found that parents/caregivers reports, underestimated the prevalence of overweight/obesity prevalence in their children and discrepancies increased as the children's age increased. For example in 2006, a sample of Belgian parents were invited to fill out a questionnaire and provide their child's (pre-school aged 3-7) height and weight in order to estimate BMI (Huybrechts et al., 2006). This study found that the mean difference between reported and measured weight led to an underestimate of 0.56 kg, the mean difference in height was overestimated by 0.14 cm, resulting in a BMI underestimated by 0.51 kg/m^2. This study also found that reported weight and height values used for BMI underestimated the prevalence of overweight and obesity (international classification) by 3.0% and 0.6%. The authors concluded that parent reports for their children's height and weight for BMI classification should not be used in research as they were too inaccurate (Huybrechts et al., 2006). In a sample of Dutch parents and their children, a questionnaire was administered requesting information on their children's height and weight (Scholtens et al., 2007). This study found that weight was underestimated by 0.1 kg, height was overestimated by 0.4 cm for males and 0.5 cm for females resulting in an overall BMI underestimated by 0.1 kg/m^2. The prevalence of overweight was underestimated by 4.0% and nearly 10.0% of children's BMI were misclassified based on reported values. Based on the level of misclassification, the authors questioned the use of parent/caregiver reported height and weight in place of measured values (Scholtens et al., 2007). Similarly, in a German study, parents were mailed a survey and were asked to report their children's height and weight (Brettschneider et al., 2012). Research found the mean differences for measured and reported values ranged across age groups. Height was underestimated by 0.06 to 0.83 cm, weight was underestimated by 0.24 to 2.23 kg and BMI was underestimated by 0.05 to 0.79 kg/m^2, although not all differences were found to be statistically significant. In addition, it was found that the prevalence of overweight from parent-reported data (13.8%) was underestimated compared to measured overweight prevalence (14.5%). The authors concluded that parent-reported height and weight is not a valid approach for obesity research (Brettschneider et al., 2012)

Several studies in the general population have examined the validity of proxy reported height and weight in children/adolescents and their conclusions are consistent. In the general population, proxy reported height and weight is not a valid measure for BMI; however, this subject should be further examined in different populations including those with disabilities.

4.2.5 Participating in research: Persons with ID and Proxies

Studies examining the validity of proxy-reported height and weight has focused on youth in the general population, leaving a significant gap in the literature regarding parent and caregiver reports of individuals with ID, particularly adults. One possible reason for the gap is the assumption that results from studies on parent and caregiver reports from the general population can be extrapolated to parents and caregivers of individuals with ID. In addition, two reports from the United Kingdom point to a disturbing level of ignorance by health care providers towards people with ID and caregivers leading to poor health outcomes including death (Disability Rights Commission, 2006; Mencap, 2007).

Some research suggests that persons with ID often have limited understanding of healthy lifestyle choices and depend on their parents/caregivers to help meet their needs, even into adulthood (Bhaumik et al., 2008). As well, the majority of respondent-based health assessments in the ID literature use proxies in place of self-reports (Boulton, Haines, Smyth, & Fielder, 2006; Lau, Chow, & Lo, 2006) and it has been found that the validity of proxy-reports for individuals with ID may differ depending on the type of proxy-relationship (Perkins, 2007). For example, some reports have found that parents of persons with ID are better proxy respondents than paid support staff (Perkins, 2007). Other factors that may influence the validity of reports include the proxy characteristics (e.g. age, sex, and education) and how long the proxy has known the individual (Magaziner, Bassett, Hebel, & Gruber-Baldini, 1996).

The conclusions about proxy-reports for children from the general population should not be generalized to proxy-reports of individuals with ID, especially adults.

Ultimately, the use of proxy-reporting is common for people with ID, yet it is unknown if reports on height and weight for adults with ID are accurate, creating a critical gap in the literature.

4.2.6 Conclusion

It is important to better understand the measures used to determine the proportion of overweight/obesity in persons with ID. The accuracy of proxy-reporting height and weight for people with ID is unknown; by extension the validity of its derived BMI and overweight/obesity proportion is also unknown. Parents and caregivers of individuals with ID are often used as proxies and respond on behalf of persons with ID in health care and research settings. Therefore, the primary objective of this study is to examine the accuracy of proxy-reported height, weight and derived BMI in adults with ID and to determine the diagnostic performance (sensitivity, specificity, positive predictive value, negative predictive value) of proxy-report derived BMI for the identification of overweight/obesity; a secondary objective is to determine if the type of proxy influences the validity of reports.

4.3 Method

4.3.1 Study design & ethics

This study used a cross-sectional design. This design enabled us to collect proxy-reported height and weight from parents and caregivers and then immediately obtain measured data from individuals with ID; this eliminated the potential risk for bias from potential height or weight changes that can occur over time. The cross-sectional design and the minimal equipment required for the study meant that data collection could happen at multiple venues over a relatively short time. This study design eliminated the risk of dropouts inherent in cohort study designs because all information was collected from the parent or caregiver and individuals with ID at the time of initial recruitment.

Ethical approval was obtained from the University of Ontario Institute of Technology Research Ethics Board (Appendix 1) and all participants and their parents or caregivers provided informed consent before the study began (Appendices 4-6). Special Olympics Ontario also approved this study; they provided assistance in recruiting study participations by providing event information (Appendix 2).

4.3.2 Recruitment

Participants were individuals with ID (age 12 and above) registered with Special Olympics Ontario, and their parent/caregiver. A booth was set up at Special Olympics Ontario sponsored events in the Greater Toronto area. Special Olympics participants of all ages and their parents/caregivers were invited to participate in this study. Participants over the age of 18 were able to provide consent, in addition to parent/caregiver consent, and individuals under 18 were required to provide assent in addition to consent from a parent/caregiver. All participants and parents/caregivers were informed of the study's components, risks, and benefits, and were given a take-home summary information sheet.

4.3.3 Participants

This study included adults with ID registered as athletes with Special Olympics Ontario. Proper equipment was not available to accommodate individuals in wheelchairs and were therefore excluded, in addition to individuals and/or parents and caregivers who did not provide assent/consent. In total, 65 adolescents and adults with ID were recruited to participate in this study and were measured. However, for the purpose of this study only adults (n=21) with ID whose proxies, either a parent (n=16), or caregiver (n=5) reported height and weight were included in analysis. For this study 'caregiver' includes an individual paid to support a person with ID such as a Developmental Social Worker or a family friend. The validity of self-reports by individuals with ID are described in a separate manuscript.

4.3.4 Procedures

Questionnaire

At each venue, participants and parents/caregivers sat down with a trained interviewer. With a questionnaire (Appendix 9), participants were asked about their age, sex, ID etiology, level of ID, current living situation, and the type of relationship with their parents/caregiver. The level of ID was determined by using self (individual with ID) or proxy-reported information based on characteristics explained by the Diagnostic and Statistical Manual for Mental Disorders (DSM-5) (American Psychiatric Association, 2013). Parents and caregivers were then asked to estimate the height and weight of the individuals with ID. Proxy-reported height and weight were used to calculate BMI (kg/m^2), and the age and sex specific cut-off points published by the World Health Organization (WHO) were used to categorize individuals with ID as underweight (<18.5), normal weight (18.5-24.9), and/or overweight/obese (≥25) (World Health Organization, 2000). When the questionnaire was completed, individuals with ID were led to a trained investigator who measured their height and weight.

Measurements- height and weight

Height and weight were measured by a trained investigator according to guidelines provided by the Canadian Society for Exercise Physiology: Physical Activity, Fitness & Lifestyle (CSEP-PATH). A rigid stadiometer was used to measure the participant's height to the nearest 0.1 cm; the participants stood on the stadiometer without footwear, feet together, and looking straight ahead. Weight was measured and recorded to the nearest 0.1 kg using a digital scale, and without shoes and in light clothing. Data were used to calculate BMI and determine BMI classification with the WHO cut-off points (World Health Organization, 2000).

4.3.5 Statistical analysis

Part 1: Characteristics of the sample and participants

Distribution of the data was examined before analysis was conducted. Normality was assessed by calculating the mean, median, skewness, and kurtosis of proxy-reported and measured data.

The descriptive statistics of participants were determined for all participants. Proxy-reported and measured height and weight were used to determine BMI (kg/m^2) and age and sex specific BMI cut-off points defined by the WHO were used to categorize participants into BMI categories. In this study, overweight and obesity were grouped into one category (i.e. overweight/obesity). This is commonly done in past research for the general population (Brettschneider et al., 2012; Fonseca et al., 2009; Huybrechts et al., 2011; Kuczmarski et al., 2001) and if separated it would have created groups that were too small.

Part 2: Agreement between proxy-reported and measured weight, height and derived BMI

The analyses used in this study are consistent with those from a thorough, recent, and commonly cited study in the general population (De Vriendt et al., 2009). Differences between measured and proxy-reported height and weight for BMI were calculated and paired samples t-tests were used to determine if mean differences were significant different than 0. Using Cohen's d (difference between the means divided by the standard deviation), effect size was used to measure the magnitude of the differences found between measured and proxy-reported data for the total sample. According to Cohen, 0.2 represents a small effect size, 0.5 medium effect size, and 0.8 and greater represents a large effect size (Cohen, 1992). This study calculated intra-class correlations coefficients which is consistent with the approach used by De Vriendt et al. (2009) and recommended by McGraw (McGraw & Wong, 1996). The intra-class correlation coefficient was calculated to determine the level of association between the measured and reported data. No relationship between measured and reported data is indicated by a value of 0, a small correlation (0.10 to 0.29), a medium correlation (0.30 to 0.49) and a strong correlation is represented by values of 0.5 to 1.0 (Pallant, 2013). To examine how proxy-reported and measured height, weight and calculated BMI for the total sample differed visually, this study created Bland and Altman plots; they were also used as a visual aid to determine if any outliers existed (Appendices 19-21).

To determine if outliers existed in the data, this study used SPSS and the Outlier Labeling Rule (Hoaglin & Iglewicz, 1987). First, the difference between the first and third quartile of the distribution is found and is multiplied by parameter *g,* (g= 2.2). The resulting value is added to the third quartile and subtracted from the first quartile to define boundaries. Any values outside of these boundaries are considered outliers. In this study, no outliers were identified.

Part 3: Impact of proxy-reported height and weight on classification in BMI-categories

An analysis was performed to measure the level of agreement between BMI categories derived from proxy-reported and measured data. The Agresti method for comparing dependent proportions was used to assess the difference in proportion of each BMI category and calculate the 95% confidence interval (CI) (Agresti & Finlay, 1997). Corresponding p-values were calculated using McNemar's test. To examine how many individuals were classified correctly, or in adjacent weight categories, a cross-tabulation was performed between proxy-reported and measured weight categories.

Sensitivity and specificity of the proxy-reported overweight/obesity BMI categories were calculated using the BMI derived from measured variables as the standard. In addition, this study determined the positive predictive value ((PPV) the proportion of individuals who are classified in a BMI category correctly) and the negative predicative value ((NPV) the proportion of individuals who were classified in an incorrect BMI category). The kappa (κ) statistic was used to assess the agreement of BMI categories determined from measured and proxy-reports (Pallant, 2013). Kappa values range from disagreement (-1.00) to full agreement between values (1.00). Poor agreement is represented by values below 0.20, values between 0.61 and 0.80 represent good agreement and very good agreement are values above 0.8 (Hulley et al., 2007).

Part 4: Agreement and impact of proxy-report derived BMI based on type of proxy

Statistical tests were repeated to examine the difference in validity based on type of proxy (parent vs. caregivers). Tests that were performed include an outlier calculation, agreement between measured and proxy-reported data, impact of proxy-reported height and weight on BMI classification, misclassification analysis and sensitivity and specificity of overweight/obesity categorization. Sensitivity and specificity were not performed for caregiver proxies due to the small sample size.

4.4 Results

Part 1: Characteristics of the sample and participants

Table 1 presents the characteristics of participants with ID (n=21) and their parents/caregivers. The majority of participants were between the ages of 20 and 29 (57.1%), of which 61.9% reported having a mild ID. Approximately 76.0% of proxies were a parent, others included paid caregivers and a family friend, and 76.2% of proxies were female. The majority of participants lived at home with their family (85.7%). Based on proxy-reported height and weight, 62.0% (n=13) were reported as being overweight/obese. Measured data found the same proportion of individuals were classified as overweight/obese as data from proxy-reported sources. Both proxy-reported and measured data found that females were less likely to be overweight/obese compared to males.

Table 1.
Descriptive information of study participants by BMI status, level of intellectual disability, proxy information and living arrangement

	Males (n=11)		Females (n=10)		Total (n=21)	
	n	%	n	%	n	%
Age of individual with ID						
20-29	7	63.6	5	50.0	12	57.1
30-39	3	27.3	5	50.0	8	38.1
40-49	1	9.1	0	0	1	4.8
Level of ID						
Mild	6	54.5	7	70.0	13	61.9
Moderate	5	45.5	3	30.0	8	38.1
Weight status for adults with ID (based on measured height and weight)						
Underweight	0	0	2	20.0	2	9.5
Normal weight	3	27.3	3	30.0	6	28.6
Overweight/Obese	8	72.7	5	50.0	13	62.0
Weight status for adults with ID (based on proxy-reported height and weight)						
Underweight	0	0	2	20.0	2	9.5
Normal weight	3	27.3	3	30.0	6	28.6
Overweight/Obese	8	72.7	5	50.0	13	62.0
Proxy Relationship						
Parent	6	54.5	10	100.0	16	76.2
Paid Caregiver	4	36.4	0	0	4	19.0
Other	1	9.1	0	0	1	4.8
Proxy Sex						
Female	7	63.6	9	90.0	16	76.2
Male	4	36.4	1	10.0	5	23.8
Living arrangement						
At family home	8	72.7	10	100.0	18	85.7
In group home	2	18.2	0	0	2	9.5
Independent	1	9.1	0	0	1	4.8

Part 2: Agreement between proxy-reported and measured weight, height and derived BMI

The proxy-reported and measured height, weight and derived BMI data for all participants are presented in table 2. Based on the paired t-test, it was found that the majority of differences between measured and proxy-reported data for the total population were not statistically significant (weight difference= 0.84 kg, p=0.592 and

BMI difference= 1.19 kg/m^2, p=0.064), except for the difference between height (2.72 cm, p=0.011).

Females tended to overestimate their height (3.02 cm), and underestimate their weight (0.16 kg) resulting in an underestimated BMI (0.99 kg/m^2). The effect size between females reported and measured weight and derived BMI (0.010, 0.142); the effect size for height was smaller (0.009). Consistent with these effect sizes, females' measured and reported height, weight and derived BMI were highly correlated (0.990, 0.930, 0.964).

Males overestimated their height by 2.45 cm, and they underestimated their weight by 1.46 kg leading to an underestimated BMI by 1.38 kg/m^2. The effect sizes for the difference between measured and reported height, weight and derived BMI were 0.339, 0.118 and 0.385. The proxy reported data were highly correlated (0.903, 0.752, 0.562) with the measured data. No outliers were found.

Table 2.

Comparison of proxy-reported and measured height, weight and derived BMI for females, males and the total sample

	Measured	Proxy-report	Difference in Mean		p-value[b]	Cohens d[c]	ICC[d]
	Mean (SD), *Median*	Mean (SD), *Median*	Mean (*SD*)	95% CI[a]			
Female Adults (n= 10)							
Weight (kg)	63.8 (19.7), *59.2*	63.6 (18.8), *60.1*	0.16 (2.85)	-1.88 - 2.19	0.866	0.010	0.990
Height (cm)	156.3 (12.1), *160.5*	159.3 (10.4), *162.6*	-3.02 (4.49)	-6.23 - 0.19	0.062	0.266	0.930
BMI(kg/m^2)	26.2 (7.12), *25.3*	25.2 (6.98), *24.8*	0.99 (1.90)	-0.38 - 2.35	0.136	0.142	0.964
Male Adults (n= 11)							
Weight (kg)	80.5 (13.8), *82.1*	78.9 (13.3), *79.4*	1.46 (9.54)	-4.96 - 7.86	0.624	0.118	0.752
Height (cm)	168.9 (9.95), *166.3*	172.4 (10.7), *172.0*	-2.45 (4.63)	-5.56 - 0.65	0.109	0.339	0.903
BMI(kg/m^2)	28.2 (4.18), *27.5*	26.8 (2.99), *26.6*	1.38 (3.48)	-0.96 - 3.72	0.218	0.385	0.572
Total Adults (n= 21)							
Weight (kg)	72.5 (18.5), *67.9*	71.7 (17.6), *70.8*	0.84 (7.05)	-2.37 - 4.04	0.592	0.044	0.925
Height (cm)	162.8 (12.5), *163.4*	165.6 (12.4), *165.1*	-2.72 (4.46)	-4.75 - -0.69	0.011*	0.225	0.935
BMI(kg/m^2)	27.2 (5.71), *26.4*	26.0 (5.21), *26.6*	1.19 (2.78)	-0.07 - 2.46	0.064	0.220	0.874

[a] 95% CI: 95% confidence interval
[b] According to the paired-samples T test
[c] *Cohen's d* values calculated as effect size
[d] Intra-class correlation coefficient
* $p < 0.05$.

Part 3: Impact of proxy-reported height and weight on classification in BMI-categories

Participants BMI-categories according to the WHO cut-off criteria for proxy-reported and measured data are presented in Table 3. The proportion of individuals in each category by proxy-reporting were the same found by measured data.

Table 3.

Proxy-reported and measured proportion of adults with ID in different BMI categories according to the World Health Organization (WHO) cutoffs

	Measured		Proxy-reported	
	%	(n)	%	(n)
Females (n=10)				
Underweight	20.0	2	20.0	2
Normal weight	30.0	3	30.0	3
Overweight/Obese	50.0	5	50.0	5
Males (n=11)				
Underweight	0	0	0	0
Normal weight	27.3	3	27.3	3
Overweight/Obese	72.8	8	72.8	8
Total (n=21)				
Underweight	9.5	2	9.5	2
Normal weight	28.6	6	28.6	6
Overweight/Obese	62.0	13	62.0	13

[a] Difference in proportion of underweight, normal weight, overweight/obesity were obtained using the Agresti method for comparing dependent proportions
[b]According to McNemar's test

The number and percentage of adults with ID classified in the correct and adjacent BMI-categories according to their proxy-reported and their measured results are presented in table 4. It was found that proxies of females with ID correctly classified all individuals with ID, whereas proxies of males with ID misclassified 4 individuals in adjacent BMI-categories. In the total sample, 17 (80.9%) adults with ID were classified in the correct BMI category, and 4 (19.0%) were misclassified in the adjacent BMI-category. Of these classifications, 2 (9.5%) individuals were reported as overweight/obese, when they were actually normal weight and 2 (9.5%) parent/caregivers reported the participant as normal weight when they were actually overweight or obese.

Table 4.

The number and proportion of adults with ID classified in different BMI categories based on proxy-reported and measured height and weight

		BMI-category based on Measured BMI						Total	
		Underweight		Normal weight		Overweight/obese			
		n	(%)	n	(%)	n	(%)	n	(%)
BMI-category based on proxy-reported BMI	**Females with ID (n=10)**								
	Underweight	2	20.0	0	0.0	0	0.0	2	20.0
	Normal weight	0	0.0	3	30.0	0	0.0	3	30.0
	Overweight/ Obese	0	0.0	0	0.0	5	50.0	5	50.0
	Total	2	20.0	3	30.0	5	50.0	10	100
BMI-category based on proxy-reported BMI	**Males with ID (n=11)**								
	Underweight	0	0.0	0	0.0	0	0.0	0	0.0
	Normal weight	0	0.0	1	9.1	2	18.2	3	27.3
	Overweight/ Obese	0	0.0	2	18.2	6	54.6	8	72.8
	Total	0	0.0	3	27.3	8	72.8	11	100
BMI-category based on proxy-reported BMI	**Total sample with ID (n=21)**								
	Underweight	2	9.5	0	0.0	0	0.0	2	9.5
	Normal weight	0	0.0	4	19.0	2	9.5	6	28.6
	Overweight/ Obese	0	0.0	2	9.6	11	52.3	13	62.0
	Total	2	9.5	6	28.6	13	62.0	21	100

Values in highlighted boxes represent accurate classification by self-report

The diagnostic performance of proxy-based data for identifying overweight/obesity in adults with ID are presented in table 5. The sensitivity and specificity for diagnosing overweight/obesity in females was 100.0%. For males participants' sensitivity and specificity was 75.0% and 33.3%. For the total sample, sensitivity was 84.6% and specificity was 75.0%. Eighty-four percent of individuals reported as overweight/obese were truly overweight/obese (i.e. the positive predictive value (PPV)). Seventy-five percent of participants who reported as not being overweight/obese were accurate (i.e. negative predictive value (NPV)).

Table 5.

Diagnostic performance of proxy-reported height and weight for determining overweight/obesity in adults with ID

	Sensitivity		Specificity		PPV[a]		NPV[b]		Kappa statistic
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%
Females (n=10)									
BMI Category									
Overweight/ Obese	100.0	46.3 - 100.0	100.0	46.3 - 100.0	100.0	46.3 - 100.0	100.0	46.3 - 100.0	1.00
Male (n=11)									
BMI Category									
Overweight/ Obese	75.0	35.6 - 95.6	33.3	1.77 - 87.5	75.0	35.6 - 95.6	33.3	1.77 - 87.5	0.083
Total (n=21)									
BMI Category									
Overweight/ Obese	84.6	53.7 - 97.3	75.0	35.6 - 95.6	84.6	53.7 - 97.3	75.0	35.6 - 95.6	0.596

[a] Positive Predictive Value, [b] Negative Predictive Value

Part 4 a): Agreement and impact of proxy-report derived BMI based on type of proxy

Proxy-reported and measured height, weight, and derived BMI results for participants with ID were stratified according to proxy relationship type (Table 6). For parent reports, the difference in BMI was found to be statistically significant (p<0.03), and for caregiver versus measured data, height difference was found to be statistically significant (p<0.02). Parents of individuals with ID slightly overestimated height (2.31 cm) and underestimated weight and the calculated BMI (1.03 kg and 1.09 kg/m^2). The measured and parent-reported values for height, weight and derived BMI were highly correlated (ICC= 0.937, 0.991, 0.959) and effect sizes were small (0.173, 0.050, 168). The caregiver-reports also slightly overestimated height (4.04 cm) and underestimated weight and derived BMI (0.22 kg and 1.53 kg/m^2). It was found that measured and caregiver reported height was highly correlated (ICC= 0.932), but weight and derived BMI had small correlation relationships for caregivers (ICC= 0.132, 0.289). Caregiver reported height resulted in a large effect size (0.672), and weight and derived BMI had small and medium effect sizes (0.016, 0.382). The inconsistent results when examining effect size vs. correlation values were likely due to 'notoriously' unstable correlation coefficients due to the small sample size (Cook, 2012).

Table 6.

Proportion of adults with ID in different BMI categories according to source of data (proxy-reported vs. measured height and weight), the World Health Organization (WHO) cutoffs and proxy type

	Measured	Proxy-report	Difference in Mean		p-value[b]	Cohen's d[c]	ICC[d]
	Mean (SD), *Median*	Mean (SD), *Median*	Mean (SD)	95% CI[a]			
Parent reports (n= 16)							
Weight (kg)	71.9 (20.3), *70.0*	70.9 (19.3), *65.8*	1.03 (2.78)	-0.45 - 2.52	0.080	0.050	0.991
Height (m)	162.7 (14.1), *163.9*	165.1 (13.6), *163.9*	-2.31 (4.92)	-4.94 - 0.31	0.159	0.173	0.937
BMI(kg/m^2)	26.9 (6.11), *25.9*	25.9 (5.81), *25.9*	1.09 (1.74)	0.16 - 2.02	0.025*	0.168	0.959
Caregiver reports (n= 5)							
Weight (kg)	74.5 (12.8), *81.5*	74.3 (11.9), *72.6*	0.22 (14.8)	-18.1 - 18.6	0.975	0.016	0.289**
Height (m)	163.3 (6.39), *162.8*	167.3 (5.48), *167.6*	-4.04 (2.37)	-6.98 - -1.10	0.019*	0.672	0.932**
BMI(kg/m^2)	27.9 (4.70), *27.7*	26.4 (2.94), *26.6*	1.53 (5.21)	-4.93 - 7.99	0.546	0.382	0.132**

[a] 95% CI: 95% confidence interval
[b] According to the paired-samples T test
[c] *Cohen's d* values calculated as effect size
[d] Intra-class correlation coefficient
* $p < 0.05$.
** Result likely unstable due to small sample size

Part 4 b): Agreement and impact of proxy-report derived BMI based on type of proxy

The proportion of BMI-categories of adults with ID based on their proxy-type were determined and presented in Table 7. Parents overestimated normal BMI proportion and underestimated the proportion of overweight/obesity in adults with ID. The reverse was seen in caregivers who underestimated the proportion of normal BMI and overestimated the proportion of overweight/obesity. McNemars' test found that the difference in proportion in weight categories were not statistically significant.

Table 7.

Categorizations of adults with ID in different BMI categories according to type of proxy, the World Health Organization (WHO) cutoffs, and differences between proxy-reported and measured proportion in each category

	Proxy-reported		Measured		Difference[a]		*p*[b]
	%	(n)	%	(n)	%	95% CI	
Parents (n=16)							
Underweight	12.5	2	12.5	2	0		
Normal weight	31.3	5	25.0	4	6.3	-0.15 - 0.27	1.00
Overweight/Obese	56.3	9	62.6	10	-6.3	-0.27 - 0.15	1.00
Caregivers (n=5)							
Normal weight	20.0	1	40.0	4	-20.0	-0.55 - 0.15	1.00
Overweight/Obese	80.0	4	60.0	3	20.0	-0.15 - 0.55	1.00

[a] Difference in proportion of underweight, normal weight, overweight/obesity were obtained using the Agresti method for comparing dependent proportions
[b]According to McNemar's test

The diagnostic performance of proxy-based data to identify overweight/obesity in adults with ID by parents and caregivers are presented in table 8. The sensitivity for overweight/obesity from parent reports was 80.0% and the specificity was 83.3%. The PPV for parent reports indicated 88.9% of participants reported as overweight/obese were truly overweight/obese, and 71.4% of participants reported by parents as not overweight/obese were truly not overweight/obese (NPV). This calculation could not be repeated for those with caregiver proxies due to small numbers.

Table 8.

Diagnostic performance of parent-reported height and weight for determining overweight/obesity in adults with ID (n=16)

	Sensitivity		Specificity		PPV[a]		NPV[b]		Kappa statistic
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%
BMI Category									
Overweight/ Obesity	80.0	44.2 - 96.5	83.3	36.5 - 99.1	88.9	50.7 - 99.4	71.4	30.3 - 94.9	0.613

[a] Positive Predictive Value, [b] Negative Predictive Value

4.5 Discussion

4.5.1 Summary of findings

The first objective of this study was to examine the accuracy of proxy-reported height and weight and derived BMI values in Special Olympics participants. This study found that the mean difference between proxy-reported and measured height and weight data were not very large; proxy-reported and measured values were highly correlated and the standard deviations of the differences were not large. It was found that proxies of females with ID were better at reporting weight and derived BMI than proxies for males with ID. All proxy-reports had a high sensitivity and slightly lower specificity for overweight/obesity proportion, but the confidence intervals were very wide and 19.0% of the sample were placed in incorrect BMI-categories. Weight and BMI differences were not statistically significant, but height was found to be statistically significant, indicating the difference did not occur by chance.

The second objective of this study was to conduct a sub-group analysis: investigate if the type of proxy, such as a parent or a caregiver, was associated with differences in the validity of proxy-reported height, weight and derived BMI. It was found that reports by parents of individuals with ID compared to measured values were all highly correlated.

Parents were more likely to underestimate the proportion of overweight/obese in their children; some statistical tests were not performed for caregiver proxies, as results from the small sample size were deemed unreliable. Overall, the differences between measured and proxy-reported values were small, but the wide confidence intervals for sensitivity and specificity and the possibility of over or underestimating the proportion of overweight/obesity justifies further study with a larger sample.

4.5.2 Interpretation of findings in light of previous research

Part 1: Characteristics of the sample and participants

Twenty-one individuals from Special Olympics Ontario participated in this study and their caregivers reported their height and weight. Compared to studies in the general population, this sample size was very small. Samples sizes from studies using the general population ranged from approximately 300 (Huybrechts et al., 2006) to 9000 (Brettschneider et al., 2012). A large sample size was not feasible for the current study; however, the results are useful as it is the first study to examine proxy-reported height and weight in individuals with ID. Just over half of the Special Olympics study participants were male (52.4%, n=11), and 47.6% (n=10) were female which is a similar distribution to the studies in the general population (Brettschneider et al., 2012; Huybrechts et al., 2006; Scholtens et al., 2007). In this study, the majority of proxy reports came from parents (76.2%, n=16) with the remaining being from caregivers such as paid support workers; this is different from studies on the general population which did not collect height and weight reports from proxies other than parents. This study chose to collect caregiver reports, as well as parent reports, because individuals with ID who participate in Special Olympics often have support workers, paid caregivers, or family friends assist them in traveling to events.

Part 2: Agreement between proxy-reported and measured weight, height and derived BMI

Studies in the general population have examined the validity of proxy-reported height and weight in children and adolescents, compared to measured values. These studies consistently concluded that proxy-reported height and weight are not valid (Brettschneider et al., 2012; Huybrechts et al., 2006; Scholtens et al., 2007). To the best of our knowledge, the current study is the first to have examined the validity of proxy-reported height and weight on behalf of individuals with ID.

Some of our study's results are comparable to those from the general population. We found that proxy-reported height for females and males was overestimated. This is consistent with a study where proxies for male and female children tended to slightly overestimate their height (0.4 cm and 0.5 cm) (Scholtens et al., 2007). However, Brettschneider et al. (2012), found that proxies for boys and the majority for females tended to underestimate height. Our study also found that proxies of Special Olympic participants underestimated weight for both sexes; in combination with reported height this led to an underestimated BMI. Similar to this result, the general population found that males and females weight and derived BMI were underestimated by proxies (Brettschneider et al., 2012; Scholtens et al., 2007), but Scholtens et al. (2007) found that weight for females was slightly overestimated.

Looking at our sample as a whole, height was overestimated and weight and calculated BMI were underestimated which is the same pattern as reported for studies from the general population (Huybrechts et al., 2006). Our results found that only the difference in height for the total sample was statistically significant, a result difficult to contrast to the reports from the general population who inconsistently report on statistical significance (Scholtens et al., 2007).

We also found that the standard deviations for the mean differences in height, weight and derived BMI were high. These values indicate that there was a great deal of variability in the accuracy of proxy-reports for each participant. Connor Gorber et al. (2007), state that large standard deviations for mean differences can substantially modify BMI classification and may lead to under or overestimated proportion of overweight/obesity. For proxy-reporting studies found in the general population, the standard deviation of the mean differences ranged from small to relatively large (Brettschneider et al., 2012; Scholtens et al., 2007), which may in part explain their conclusion that proxy-reports are not valid.

We found that the effect size for all the total sample mean differences were below or around 0.2, indicating a small effect. The studies examining proxy-reported height and weight in the general population did not report any measure of effect size, rather the relationship between proxy-reported and measured data were measured with intra-class correlation coefficients. The results from our study show that correlation coefficients of proxy reports for males, females and the total sample ranged from 0.572 to 0.990, indicating a high correlation between measured and proxy-reported values and were similar to results presented in the general population (Scholtens et al., 2007). However, high correlations are not considered sufficient reason to recommend proxy-reports as valid. It has been reported that high correlations do not imply good agreement between two measurements and should not be solely used to determine which method is best (De Vriendt et al., 2009).

Part 3: Impact of proxy-reported height and weight on classification in BMI-categories

When using proxy-reported height and weight for BMI classification according to the WHO age and sex specific cut-off points, our study found that the number of individuals in each weight category was the same as measured results: 62.0% were found to be overweight/obese.

Although it appeared that the number of individuals categorized as overweight/obese was the same from proxy-reported and measured data (Table 3), in effect only 80.9% of participants were classified in the correct BMI category (Table 4). Misclassification errors occurred at the level of the individual, causing 19.1% (4 participants) of the total sample to be placed in an incorrect BMI-category based on proxy-reports. Misclassification errors also took place in studies from the general population. Scholtens et al. (2007) found 9.7% (84 participants) were misclassified, of which 73.8% (62 participants) were classified in a lower BMI category when using proxy-reported results. Brettschneider et al. (2012) found that 41.5% of females and 31.5% of males were misclassified as something other than overweight/obese by proxy-reports, when they were truly overweight/obese. Huybretchs et al. (2006) found that 4.7% (n=14) were grossly misclassified and 31.3% (n=93) were misclassified in the adjacent category. Overall, it is suggested that a screen is of poor validity when it is not able to detect a large amount of cases, such as overweight/obesity (Elgar & Stewart, 2008). Proxy-reports misclassified approximately 1 in 3 cases of obesity (Elgar & Stewart, 2008), whereas our study found that approximately 1 in 6 cases of overweight/obesity cases were misclassified. Therefore, our misclassification level is better than studies in the general population, and did not miss a large amount of overweight/obesity cases. Therefore, based on this proxy-reported height and weight for overweight/obesity data is considered valid.

This study found that in the total sample, overweight/obesity classification based on proxy-reported data had a sensitivity of 84.6% and a specificity of 75.0%. The PPV was found to be 84.6%, the NPV was 75.0% and the kappa statistic was 0.596. These results indicate that the diagnostic ability of proxy-reports to identify overweight/obesity in persons with ID was moderate (kappa statistic); however, the confidence intervals for sensitivity and specificity were wide. The wide confidence intervals emphasize the small sample size and thus lack of power in this study. Our results are different than those from the general population where specificity for overweight/obese groups were higher than sensitivity (Brettschneider et al., 2012; Huybrechts et al., 2006). Unlike the general population, sensitivity for our population was high and a high sensitivity is desired in proxy-reported height and weight screen tests, as those who are truly overweight/obese and may need interventions, will not be missed (Kuczmarski et al., 2001). A high sensitivity corresponds to a low false negative rate which means that there is a low likelihood of missing cases of overweight/obese.

Part 4: Agreement and impact of proxy-report derived BMI based on type of proxy

We found that parent proxies were better at reporting height and derived BMI compared to caregiver proxies, but were less accurate in reporting weight. The differences in measured and reported height, weight and derived BMI in parents was underestimated by 1.09 kg/m^2, and caregivers underestimated reported height and weight for BMI by 1.53 kg/m^2. The correlation values for parent reports were all close to 1, and effect sizes closer to 0. There were some inconsistencies found with the correlation and effect sizes from caregivers for weight and derived BMI, which were both very small; these results may be due to the extremely small sample size for the caregiver group.

When examining proxy reports from parents we found the resulting overweight/obese proportion was underestimated, while reports from individuals who were paid caregivers or family friends led to an overestimate of the proportion of overweight/obesity. A reason for this difference may be that caregivers have not known the adults with ID for very long, and were guessing based on their preconceptions of what the participant looked like, rather than previous height and weight measurements. We found the ability of parents to correctly categorize overweight/obesity was good, with a sensitivity of 80.0% and a specificity of 83.3%, but the confidence intervals were wide. Sensitivity and specificity for caregiver reports were not calculated due to the small sample size.

4.5.3 Strengths and limitations

There were strengths to our study. Firstly, to our knowledge, this is the first study to examine the validity of proxy-reported height and weight on behalf of persons with ID; therefore, this study addresses a gap in the literature and helps lay groundwork for future research in this area. A second strength is that even though the participants in this study are adults, the data collection situation was realistic. Individuals with ID often rely on their parents/caregivers to answer health related questions whether in clinical situations or for research. Proxy responses to questions on height and weight for Special Olympics participants or any individual with ID is likely a common occurrence. A third strength is the use of a cross-sectional design; since there was no time delay between proxy-report and direct measurement, there was no opportunity for actual weight or height to change and potentially bias the results. Lastly, this study conducted an outlier calculation which many studies fail to report on (Brettschneider et al., 2012; Huybrechts et al., 2006; Scholtens et al., 2007).

There were also a number of limitations to our study. The first limitation is the small sample size which reduced our statistical power and ability to determine if the differences between proxy-reported and measured values were statistically significant. The second limitation is this study found that sensitivity of proxy-reports was lower for males with ID compared to females with ID, these findings are probably influenced by the low sample size. In addition, the representation of males and females was not what is typically seen in prevalence studies of individuals with ID (Maulik et al., 2011). These limitations support the need for a larger representative sample. The third limitation is when groups were stratified according to proxy-type, group sizes were imbalanced; reliable calculations for the caregivers were not possible. A fourth limitation arises from the study population consisting of Special Olympics Ontario participants. Not all Special Olympics Ontario participants are elite athletes, however, they likely participate in sport and exercise more than their peers who may not engage in physical activity. Consequently, the sample of individuals from Special Olympics Ontario may not be generalizable to all individuals with ID. Despite these study limitations, we found that differences in proxy-reported height, weight and derived BMI were not large, and the proportion of individuals in each category were the same from measured and reported data; but misclassification of weight categories occurred, suggesting further research is needed using a larger sample.

4.5.4 Implications and future research

Parents/caregivers of individuals with ID often answer health and research related questions on their behalf. Parents/caregivers of individuals with ID may be faced with survey questions on height and weight to determine the proportion of overweight/obesity; this study begins to determine the validity of these reports and whether they can be used in place of measured data. This study found that proxies tended to overestimate height and underestimate weight and calculated BMI, but the differences were not large, and were highly correlated; the sensitivity of proxy-reporting versus measured results to determine overweight/obesity were relatively high, but specificity was low. These results show that proxies of individuals with ID may be somewhat accurate at reporting height and weight for BMI. But since overweight/obesity proportion is a serious issue with health implications, these findings need to be replicated before concluding that proxy-reports can be used in place of the gold standard of physical measurement.

The studies using samples from the general population all concluded that proxy-reported height and weight for overweight/obesity proportion should not be relied on. However, among these studies, the statistical analysis methods and reasons to not rely on proxy-reported height and weight data were not consistent. The studies from the general population have not yet determined how much of a difference in proxy-reported and measured data is too large to reject or small enough to accept the use of proxy reports; therefore we could not apply a standard to our study. As well, they do not consistently report relevant statistics such as mean differences, sensitivity and specificity, and misclassification analysis. Although these studies consistently reported that proxy-reported height and weight for BMI should not replace measured data, this area of research can be further improved by determining which statistical tests are of most importance in determining the validity of results.

Our sample only included adult individuals with ID, yet proxy-reporting is common among individuals with ID of all ages. We suggest that future research should further examine the validity of proxy-reported height and weight in individuals of all ages with ID. It is also important to determine if factors such as proxy socio-economic status, personal weight categorization, and length of relationship with the individual with ID influences the validity of proxy-reports. Future studies should use a sample size similar to those used in the general population and access a source population considered representative of all individuals with ID. Lastly, some readers may consider this pilot work since it is the first of its kind, but it provides useful methodology and results to guide future research.

4.5.5 Conclusion

The primary objective of this study was to examine the accuracy of proxy-reported height, weight and derived BMI in persons with ID. We found that proxy-reports of individuals with ID were not significantly different from 0, but overestimated height, and underestimated weight and derived BMI, which led to several participants being placed in incorrect BMI categories. The second objective of this study was to determine if the type of proxy influenced the validity of reports and the under or overestimation of overweight/obesity proportion. Upon analysis, it appears parents were more accurate at reporting height and weight for BMI, but the small sample size of caregivers made results from this group unreliable. These preliminary findings suggest that parents and caregivers as a group may be fairly accurate at reporting for individuals with ID, but since some participants were classified into incorrect BMI categories the results should call into question the use of proxy-reports for prevalence studies. Overall, based on these results proxy-reported height and weight for individuals with ID cannot be validated. This study was the first of kind, consequently, additional research is necessary to further examine the validity of proxy-reports in larger samples of individuals with ID.

5 THESIS CONCLUSIONS

5.1 Thesis Conclusions

5.1.1 Summary

An Intellectual disability (ID) is a disability that influences intellectual functioning and adaptive behavior limiting a person's ability to perform everyday activities (American Association on Intellectual and Developmental Disabilities, 2013). Compared to the general population, individuals with ID experience many complex health problems including a greater risk for overweight/obesity (de Winter et al., 2012; Foley et al., 2013; Stedman & Leland, 2010). The high prevalence of overweight/obesity in persons with ID further compromises their health because they are associated with decreased quality of life, increased risk for depression and they can diminish social and physical functioning (Rimmer et al., 2010). To obtain overweight/obesity proportions, height and weight data are collected to calculate BMI values. The gold standard of physical measurement is not often feasible due to time and money constraints, and therefore large studies rely on self or proxy-reported height and weight (Connor Gorber et al., 2007; Morrissey et al., 2006). In general, proxy-reporting for individuals with ID is much more common than self-reports, due to the belief that individuals with ID have characteristics which decrease the validity of reports (Breau & Burkitt, 2009), such as the level of ID (Perkins, 2007). Self-reported height and weight for BMI in the general population has been found to underestimate the proportion of overweight/obesity (Brunner Huber, 2007; Elgar & Stewart, 2008; John et al., 2005; Kuczmarski et al., 2001), and the same has been found regarding proxy-reports (Brettschneider et al., 2012; Huybrechts et al., 2006; Scholtens et al., 2007); yet, we do not know if this trend is consistent in individuals with ID, particularly because they have not been included in related validity research thus far.

Engaging in activities such as reporting on health issues including height and weight, provides a number of benefits including health awareness, self-expression, and choice (Fujiura, 2012) and addresses the activity component of the WHO-ICF framework (World Health Organization, 2001a). In an effort to encourage greater participation of individuals with ID in society it is critical that they be given the chance to be active agents in their lives. This includes opportunities for the individual with ID and their caregiver to participate in research and in clinical encounters in order that they may benefit from findings and so that they (and their health professionals) can better understand their health; this addresses the participation and environmental factors of the WHO-ICF framework (World Health Organization, 2001a). Principles from the Convention on the Rights of Persons with Disabilities state that people with disabilities should have "full and effective participation and inclusion in society" and "equality of opportunity"; in our opinion this should extend to the opportunity to actively participate in and benefit from research (United Nations General Assembly, 2007). This thesis is consistent with the principles of the WHO-ICF and the Convention for the Rights of Persons with Disabilities by including people with ID in the research process starting with informed consent, by seeking their responses to questionnaire items and including their caregivers in the process. The primary objective of this research was to better understand the accuracy of self and proxy-reported height and weight for the derivation of BMI in persons with ID. The secondary objective was to understand how the validity of self-reports may differ based on the level of ID and how the validity of proxy-reports differ based on type of proxy relationship. The results from this study demonstrated that individuals with ID were accurate at reporting their height and weight for calculated

BMI. The differences in measured and reported data were not large, and were not found to be statistically significant. One outlier report was found and, when removed, proved differences in measured and reported data were even closer to zero, suggesting validity between reports. We found high sensitivity for categorizing overweight/obese using self-reported data. Persons with mild ID were more accurate at reporting height and weight for BMI, when an outlier was removed; but, individuals with moderate ID were also very accurate. This may have been influenced by their ability to consult with caregivers before self-reporting. These findings demonstrated that individuals with ID are able to accurately report height and weight for BMI. The severity level of ID did not have a large effect on results. We therefore consider self-reports from people with mild and moderate ID useful when physical measurements are not feasible.

Proxies for individuals with ID were also fairly accurate at reporting height and weight for calculated BMI. The differences in measured and reported data were not large and, in most part, not statistically significant. The analysis of BMI categorization by proxy-reports found that a large proportion of individuals were classified in the correct weight categories. However, the sensitivity of proxy-reporting overweight/obesity was not as high as desired. In regards to type of caregiver reports, it was found that parents reported height and weight more accurately, but the resulting sensitivity for reporting overweight/obesity was not has high as caregiver reports. These results indicate that when physical measurement is not feasible, proxy-reports may be a useful alternative, but since the sensitivity of reporting overweight/obesity was not very high and the sample size was small, proxy-reported height and weight for BMI in persons with ID cannot be recommended with confidence.

In order to facilitate a comprehensive understanding of the recommendations from both manuscripts, we have created a diagram that describes our results using an algorithm (see appendix 22).

5.1.2 Future research recommendations

The findings from the current study merit future research investigating the validity of self and proxy-reported height and weight for BMI in individuals with ID. Ideally, future studies should implement a cross-sectional study design; examine younger age groups; include larger sample sizes; and obtain precise ID level of functioning and diagnoses. Future studies should also implement the study outside of events held by Special Olympics to ensure a representative sample of individuals with ID. Alternatively, since Special Olympics is a useful group to access for the recruitment of participants, a study is needed to confirm that Special Olympics participants are representative of the broader population of people with ID.

Currently, some studies have collected height and weight data from individuals with ID from physician records or from direct physical measurement, but it was unfeasible for them to achieve large population level sample sizes (De et al., 2008; Mikulovic et al., 2011; Stedman & Leland, 2010). The studies by Lloyd et al. (2012), Foley et al. (2012) and Temple et al. (2014) obtained large sample sizes using measured height and weight data from Special Olympics participants; the data are from athletes who undergo health screenings, making measured height and weight data easily attainable. Directly measured height and weight for BMI remains the gold standard and where possible, should be implemented.

We recommended that future studies examining the accuracy of proxy-reported height and weight for BMI in individuals with ID collect more demographic information. For example, it is important to determine if factors such as proxy socio-economic status, personal weight categorization, and length of relationship with the individual with ID influences the validity of their reports.

Lastly, we recommend that individuals with ID, like those in this study, should be included in research more often in order to honor their self-expression and engage them in society. It is common for individuals with ID to be excluded from research because it is believed their intellectual disability will influence the validity of reports; however, the current study has shown that reports by individuals with mild and moderate ID, specifically on height and weight, can be quite accurate. We found speaking to individuals with ID about their height and weight, as well as their proxies, sparked interests in weight loss and other healthy living practices. Asking individuals with ID and their proxies about height and weight brought more awareness to the risks of overweight/obesity. Thus, asking individuals with ID about their height and weight may be prove to be a useful technique to address health issues and improve the health of individuals with ID.

5.1.3 Conclusion

In conclusion, this study found overall that individuals with ID and their proxies can report height and weight for BMI when the gold standard of physical measurement is not feasible. This discovery allows researchers to collect overweight/obesity data in very large samples of individuals with ID and use the data to accurately guide health programs and interventions aimed at reducing overweight/obesity prevalence in persons with ID.

In addition, this research supports the inclusion of individuals with ID in research. To our knowledge, this is the first study to examine the validity of self and proxy-reported height and weight for BMI in individuals with ID. Therefore, the findings from this research fill a gap in the literature and make a contribution to the understanding of how we can easily collect overweight/obesity data from individuals with ID. Ultimately, this study recommends reports from individuals with ID become a priority in future health research, including studies on overweight/obesity.

6 Thesis References

Agresti, A., & Finlay, B. (1997). Statistical methods for the social sciences (3rd edition): Upper Saddle River, NJ: Pearson/Prentice Hall.

American Association on Intellectual and Developmental Disabilities. (2013). Definition of intellectual disability. Retrieved January 18, 2014, from http://aaidd.org/intellectual-disability/definition

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, (DSM-5®)*: American Psychiatric Pub.

Ayaso-Maneiro, J., Domínguez-Prado, D. M., & García-Soidan, J. L. (2014). Influence of weight loss therapy programs in body image self-perception in adults with intellectual disabilities. *International Journal of Clinical and Health Psychology, 14*(3), 178-185. doi: 10.1016/j.ijchp.2014.03.002

Balboni, G., Coscarelli, A., Giunti, G., & Schalock, R. L. (2013). The assessment of the quality of life of adults with intellectual disability: The use of self-report and report of others assessment strategies. *Research in Developmental Disabilities, 34*(11), 4248-4254.

Bandini, L., Curtin, C., Hamad, C., Tybor, D., & Must, A. (2005). Prevalence of Overweight in Children with Developmental Disorders in the Continuous National Health and Nutrition Examination Survey (NHANES) 1999-2002. *The Journal of Pediatrics, 146*(6), 738-743. doi: 10.1016/j.jpeds.2005.01.049

Bégarie, J., Maïano, C., Leconte, P., & Ninot, G. (2013). The prevalence and determinants of overweight and obesity among French youths and adults with intellectual disabilities attending special education schools. *Research in Developmental Disabilities, 34*(5), 1417-1425. doi: 10.1016/j.ridd.2012.12.007

Bes-Rastrollo, M., Sabaté, J., Jaceldo-Siegl, K., & Fraser, G. E. (2011). Validation of self-reported anthropometrics in the Adventist Health Study 2. *BMC public health, 11*(1), 213-213. doi: 10.1186/1471-2458-11-213

Bhaumik, S., Watson, J. M., Thorp, C. F., Tyrer, F., & McGrother, C. W. (2008). Body mass index in adults with intellectual disability: distribution, associations and service implications: a population-based prevalence study. *Journal of intellectual disability research : JIDR, 52*(Pt 4), 287-298. doi: 10.1111/j.1365-2788.2007.01018.x

Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., & Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *The journals of gerontology. Series A, Biological sciences and medical sciences, 57*(7), M470-M472. doi: 10.1093/gerona/57.7.M470

Bland, J. M., & Altman, D. G. (2010). Statistical methods for assessing agreement between two methods of clinical measurement. *International Journal of Nursing Studies, 47*(8), 931-936. doi: 10.1016/j.ijnurstu.2009.10.001

Booth, H. P., Prevost, A. T., & Gulliford, M. C. (2013). Epidemiology of clinical body mass index recording in an obese population in primary care: a cohort study. *Journal of public health (Oxford, England), 35*(1), 67. doi: 10.1093/pubmed/fds063

Boulton, M., Haines, L., Smyth, D., & Fielder, A. (2006). Health-related quality of life of children with vision impairment or blindness. *Developmental Medicine and Child Neurology, 48*(8), 656-661. doi: 10.1017/S0012162206001381

Breau, L. M., & Burkitt, C. (2009). Assessing pain in children with intellectual disabilities. *Pain Research & Management: The Journal of the Canadian Pain Society, 14*(2), 116.

Brettschneider, A.-K., Ellert, U., & Schaffrath Rosario, A. (2012). Comparison of BMI derived from parent-reported height and weight with measured values: results from the German KiGGS study. *International journal of environmental research and public health, 9*(2), 632-647.

Brunner Huber, L. R. (2007). Validity of self-reported height and weight in women of reproductive age. *Maternal and child health journal, 11*(2), 137-144.

Canadian Society for Exercise Physiology. (2013). CSEP-PATH: Physical Activity Training for Health (pp. 57-59). Ottawa: CSEP.

Casey, A. F. (2013). Measuring body composition in individuals with intellectual disability: a scoping review. *Journal of obesity, 2013*, 628428-628426. doi: 10.1155/2013/628428

Chan, A. S. Y., & Chow, B. C. (2010). Physiological and Psychosocial Health among Adults with Mental Disability: A Mini Study. *Asian Journal of Physical Education & Recreation, 16*(1), 73-78.

Cohen, J. (1992). A power primer. *Psychological bulletin, 112*(1), 155.

Connor Gorber, S., Tremblay, M., Moher, D., & Gorber, B. (2007). A comparison of direct vs. self-report measures for assessing height, weight and body mass index:

a systematic review. *Obesity Reviews, 8*(4), 307-326. doi: 10.1111/j.1467-789X.2007.00347.x

Cook, M. (2012). *Levels of personality*: Cambridge University Press.

de Kuijper, G., Hoekstra, P., Visser, F., Scholte, F. A., Penning, C., & Evenhuis, H. (2010). Use of antipsychotic drugs in individuals with intellectual disability (ID) in the Netherlands: prevalence and reasons for prescription. *Journal of intellectual disability research : JIDR, 54*(7), 659-667. doi: 10.1111/j.1365-2788.2010.01275.x

De, S., Small, J., & Baur, L. A. (2008). Overweight and obesity among children with developmental disabilities. *Journal of intellectual & developmental disability, 33*(1), 43-43. doi: 10.1080/13668250701875137

De Vriendt, T., Huybrechts, I., Ottevaere, C., Van Trimpont, I., & De Henauw, S. (2009). Validity of self-reported weight and height of adolescents, its impact on classification into BMI-categories and the association with weighing behaviour. *International journal of environmental research and public health, 6*(10), 2696-2711. doi: 10.3390/ijerph6102696

de Winter, C. F., Bastiaanse, L. P., Hilgenkamp, T. I. M., Evenhuis, H. M., & Echteld, M. A. (2012). Overweight and obesity in older people with intellectual disability. *Research in Developmental Disabilities, 33*(2), 398-405. doi: 10.1016/j.ridd.2011.09.022

Disability Rights Commission. (2006). *Equal Treatment: Closing the Gap: A formal investigation into physical health inequalities experienced by people with* *learning disabilities and/or mental health problems*: Disability Rights Commission.

Elgar, F. J., Roberts, C., Tudor-Smith, C., & Moore, L. (2005). Validity of self-reported height and weight and predictors of bias in adolescents. *Journal of Adolescent Health, 37*(5), 371-375. doi: 10.1016/j.jadohealth.2004.07.014

Elgar, F. J., & Stewart, J. M. (2008). Validity of self-report screening for overweight and obesity. Evidence from the Canadian Community Health Survey. *Canadian journal of public health = Revue canadienne de santé publique, 99*(5), 423-427.

Finlay, W. M. L., & Lyons, E. (2001). Methodological Issues in Interviewing and Using Self-Report Questionnaires With People With Mental Retardation. *Psychological Assessment, 13*(3), 319-335. doi: 10.1037/1040-3590.13.3.319

Foley, J. T., Lloyd, M., & Temple, V. A. (2013). Body Mass Index Trends Among Adult US Special Olympians, 2005--2010. *Adapted Physical Activity Quarterly, 30*(4).

Fonseca, H., Silva, A. M., Matos, M. G., Esteves, I., Costa, P., Guerra, A., & Gomes-Pedro, J. (2009). Validity of BMI based on self-reported weight and height in adolescents. *Acta paediatrica (Oslo, Norway : 1992), 99*(1), 83-83. doi: 10.1111/j.1651-2227.2009.01518.x

Fujiura, G. T. (2012). Self-reported health of people with intellectual disability. *Intellectual and developmental disabilities, 50*(4), 352-369.

George, V. A., Shacter, S. D., & Johnson, P. M. (2011). BMI and attitudes and beliefs about physical activity and nutrition of parents of adolescents with intellectual disabilities. *Journal of Intellectual Disability Research, 55*(11), 1054-1063. doi: 10.1111/j.1365-2788.2011.01437.x

Gravestock, S. (2000). Eating disorders in adults with intellectual disability. *Journal of Intellectual Disability Research, 44*(6), 625-637. doi: 10.1046/j.1365-2788.2000.00308.x

Großschädl, F., Haditsch, B., & Stronegger, W. J. (2012). Validity of self-reported weight and height in Austrian adults: sociodemographic determinants and consequences for the classification of BMI categories. *Public health nutrition, 15*(1), 20-27. doi: 10.1017/S1368980011001911

Haslam, D., Sattar, N., & Lean, M. (2006). ABC of obesity Obesity—time to wake up. *BMJ: British Medical Journal*, *333*(7569), 640-642.

Heart and Stroke Foundation of Canada. (2009). Overweight, Obesity, and Heart Disease and Stroke.

Hoaglin, D. C., & Iglewicz, B. (1987). Fine-tuning some resistant rules for outlier labeling. *Journal of the American Statistical Association*, *82*(400), 1147-1149.

Hove, O., & Havik, O. E. (2010). Developmental level and other factors associated with symptoms of mental disorders and problem behaviour in adults with intellectual disabilities living in the community. *Social psychiatry and psychiatric epidemiology*, *45*(1), 105-113.

Hulley, S. B., Cummings, S. R., Browner, W. S., Grady, D. G., & Newman, T. B. (2007). *Designing clinical research (3rd ed.)*. Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Huybrechts, I., De Bacquer, D., Van Trimpont, I., De Backer, G., & De Henauw, S. (2006). Validity of parentally reported weight and height for preschool-aged children in Belgium and its impact on classification into body mass index categories. *Pediatrics*, *118*(5), 2109-2118.

Huybrechts, I., Himes, J. H., Ottevaere, C., De Vriendt, T., De Keyzer, W., Cox, B., . . . De Henauw, S. (2011). Validity of parent-reported weight and height of preschool children measured at home or estimated without home measurement: a validation study. *BMC pediatrics, 11*(1), 63.

Jansen, W., Van de Looij-Jansen, P., Ferreira, I., De Wilde, E., & Brug, J. (2006). Differences in measured and self-reported height and weight in Dutch adolescents. *Annals of nutrition and metabolism*, *50*(4), 339-346.

Janssen, I., Katzmarzyk, P. T., Boyce, W. F., Vereecken, C., Mulvihill, C., Roberts, C., . . . The Health Behaviour in School-Aged Children Obesity Working, G. (2005). Comparison of overweight and obesity prevalence in school-aged youth from 34 countries and their relationships with physical activity and dietary patterns. *Obesity reviews : an official journal of the International Association for the Study of Obesity, 6*(2), 123-132. doi: 10.1111/j.1467-789X.2005.00176.x

John, U., Hanke, M., Grothues, J., & Thyrian, J. (2005). Validity of overweight and obesity in a nation based on self-report versus measurement device data. *European journal of clinical nutrition*, *60*(3), 372-377.

Katz, D. (2014). Perspective: Obesity is not a disease. *Nature, 508*(7496), S57-S57.

Kerr, M. (2004). Improving the general health of people with learning disabilities. *Advances in Psychiatric Treatment, 10*(3), 200-206.

Kravitz, L. (2010). Waist-to-Hip Ratio, Waist Circumference and BMI: What to use for health risk indication and why. *IDEA Fitness Journal, 7*(9), 18-21.

Kuczmarski, M. F., Kuczmarski, R. J., & Najjar, M. (2001). Effects of age on validity of self-reported height, weight, and body mass index: findings from the Third National Health and Nutrition Examination Survey, 1988–1994. *Journal of the American Dietetic Association, 101*(1), 28-34.

Lau, K.-M., Chow, S. M. K., & Lo, S. K. (2006). Parents' Perception of the Quality of Life of Preschool Children at Risk or Having Developmental Disabilities. *Quality of Life Research, 15*(7), 1133-1141. doi: 10.1007/s11136-006-0067-z

Lee, D.-H., Shin, A., Kim, J., Yoo, K.-Y., & Sung, J. (2011). Validity of self-reported height and weight in a Korean population. *Journal of epidemiology/Japan Epidemiological Association, 21*(1), 30-36.

Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D. M., & Boyle, F. (2005). Beating the barriers: recruitment of people with intellectual disability to participate in research. *Journal of intellectual disability research : JIDR, 49*(Pt 4), 296-305. doi: 10.1111/j.1365-2788.2005.00618.x

Linhart, Y., Romano-Zelekha, O., & Shohat, T. (2010). Validity of self-reported weight and height among 13-14 year old schoolchildren in Israel. *The Israel Medical Association journal: IMAJ, 12*(10), 603-605.

Lloyd, M., Temple, V. A., & Foley, J. T. (2012). International BMI comparison of children and youth with intellectual disabilities participating in Special Olympics. *Research in Developmental Disabilities, 33*(6), 1708-1714. doi: 10.1016/j.ridd.2012.04.014

Lunsky, Y., Emery, C., & Benson, B. (2002). Staff and self-reports of health behaviours, somatic complaints, and medications among adults with mild intellectual disability. *Journal of Intellectual and Developmental Disability, 27*(2), 125-135.

Lunsky, Y., Klein-Geltink, J., & Yates, E. (2013). Atlas on the primary care of adults with developmental disabilities in Ontario. Toronto, Ontario: Institute for Clinical Evaluative Sciences.

Magaziner, J., Bassett, S. S., Hebel, J. R., & Gruber-Baldini, A. (1996). Use of proxies to measure health and functional status in epidemiologic studies of community-dwelling women aged 65 years and older. *American Journal of Epidemiology, 143*(3), 283-292.

Malhotra, R., Chan, A., & Østbye, T. (2012). Validity of Proxy-Reported Weight for Older Adults. *Journal of the American Geriatrics Society, 60*(1), 189-190.

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in Developmental Disabilities, 32*(2), 419-436.

McGraw, K. O., & Wong, S. P. (1996). Forming Inferences About Some Intraclass Correlation Coefficients. *Psychological Methods, 1*(1), 30-46. doi: 10.1037/1082-989X.1.1.30

Melville, C. A., Cooper, S. A., McGrother, C. W., Thorp, C. F., & Collacott, R. (2005). Obesity in adults with Down syndrome: a case–control study. *Journal of Intellectual Disability Research, 49*(2), 125-133. doi: 10.1111/j.1365-2788.2004.00616.x

Melville, C. A., Hamilton, S., Hankey, C. R., Miller, S., & Boyle, S. (2007). The prevalence and determinants of obesity in adults with intellectual disabilities. *Obesity Reviews, 8*(3), 223-230. doi: 10.1111/j.1467-789X.2006.00296.x

Mencap, R. (2007). Death by indifference. *London, Mencap*.

Mikulovic, J., Marcellini, A., Compte, R., Duchateau, G., Vanhelst, J., Fardy, P. S., & Bui-Xuan, G. (2011). Prevalence of overweight in adolescents with intellectual deficiency. Differences in socio-educative context, physical activity and dietary habits. *Appetite, 56*(2), 403-407. doi: 10.1016/j.appet.2010.12.006

Morrissey, S. L., Whetstone, L. M., Cummings, D. M., & Owen, L. J. (2006). Comparison of Self-Reported and Measured Height and Weight in Eighth-Grade Students. *Journal of School Health, 76*(10), 512-515.

OECD. (2013). Overweight or obese population - self-reported data (age 15+). In OECD Health Data 2013, Definitions, Sources and Methods.

Pallant, J. (2013). A Step by Step Guide to Data Analysis Using IBM Spss. *Survival Manual. Washington DC: McGraw Hill*.

Perkins, E. A. (2007). Self- and Proxy Reports Across Three Populations: Older Adults, Persons With Alzheimer's Disease, and Persons With Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*(1), 1-10. doi: 10.1111/j.1741-1130.2006.00092.x

Phillips, K. L., Schieve, L. A., Visser, S., Boulet, S., Sharma, A. J., Kogan, M. D., . . . Yeargin-Allsopp, M. (2014). Prevalence and Impact of Unhealthy Weight in a National Sample of US Adolescents with Autism and Other Learning and Behavioral Disabilities. *Maternal and child health journal*, 1-12.

Pogson, D. (2012). Prader-Willi syndrome: genotype, cause, phenotype and management. *Gastrointestinal Nursing, 10*(3), 44-49.

Powell-Young, Y. M. (2012). The validity of self-report weight and height as a surrogate method for direct measurement. *Applied Nursing Research, 25*(1), 25-30.

Reel, J. J., Bucciere, R. A., & SooHoo, S. (2013). Exploring Body Image and Body Mass Index of Male and Female Special Olympics Athletes. *Journal of Clinical Sport Psychology, 7*(2), 89-97.

Rimmer, J. H., & Wang, E. (2005). Obesity Prevalence Among a Group of Chicago Residents With Disabilities. *Arch Phys Med Rehabil, 86*(7), 1461-1464. doi: 10.1016/j.apmr.2004.10.038

Rimmer, J. H., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental retardation and developmental disabilities research reviews, 12*(1), 22-27. doi: 10.1002/mrdd.20091

Rimmer, J. H., Yamaki, K., Lowry, B. M. D., Wang, E., & Vogel, L. C. (2010). Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities. *Journal of intellectual disability research : JIDR, 54*(9), 787-794. doi: 10.1111/j.1365-2788.2010.01305.x

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., & Hallam, A. (2000). Receipt of psychotropic medication by people with intellectual disability in residential settings. *Journal of intellectual disability research : JIDR, 44 (Pt 6)*(6), 666-676. doi: 10.1046/j.1365-2788.2000.00307.x

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Turner, S., Kessissoglou, S., & Hallam, A. (2000). Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities, 21*(6), 469-486. doi: 10.1016/S0891-4222(00)00053-6

Roeleveld, N., Zielhuis, G. A., & Gabreëls, F. (1997). The prevalence of mental retardation: a critical review of recent literature. *Developmental Medicine and Child Neurology, 39*(2), 125-132. doi: 10.1111/j.1469-8749.1997.tb07395.x

Salaun, L., & Berthouze-Aranda, S. E. (2011). Physical Fitness and Fatness in Adolescents with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 25*(3), 231-239. doi: 10.1111/j.1468-3148.2012.00659.x

Scholtens, S., Brunekreef, B., Visscher, T. L., Smit, H. A., Kerkhof, M., De Jongste, J. C., . . . Wijga, A. H. (2007). Reported versus measured body weight and height of 4-year-old children and the prevalence of overweight. *The European Journal of Public Health, 17*(4), 369-374.

Soler Marin, A., & Graupera, J. (2011). Nutritional status of intellectual disabled persons with Down syndrome. *Nutricion Hospitalaria, 26*(5).

Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Bershadsky, J., Taub, S., . . . Ticha, R. (2011). Overweight and obesity among adults with intellectual disabilities who use intellectual disability/developmental disability services in 20 US States. *American journal on intellectual and developmental disabilities, 116*(6), 401-418.

Stedman, K. V., & Leland, L. S. (2010). Obesity and intellectual disability in New Zealand. *Journal of intellectual & developmental disability, 35*(2), 112-115. doi: 10.3109/13668251003717928

Sullivan, W. F., Berg, J. M., Bradley, E., Cheetham, T., Denton, R., Heng, J., . . . Korossy, M. (2011). Primary care of adults with developmental disabilities Canadian consensus guidelines. *Canadian Family Physician, 57*(5), 541-553.

Temple, V., Foley, J., & Lloyd, M. (2014). Body mass index of adults with intellectual disability participating in Special Olympics by world region. *Journal of Intellectual Disability Research, 58*(3), 277-284. doi: 10.1111/jir.12011

Temple, V., Frey, G., & Stanish, H. (2006). Physical activity of adults with mental retardation: Review and research needs. *American Journal of Health Promotion, 21*(1), 2-12.

Temple, V., Walkley, J., & Greenway, K. (2010). Body mass index as an indicator of adiposity among adults with intellectual disability. *Journal of Intellectual and Developmental Disability, 35*(2), 116-120. doi: 10.3109/13668251003694598

Tjepkema, M. (2006). Adult obesity. *Health reports, 17*(3), 9.

Tremblay, M. S., Shields, M., Laviolette, M., Craig, C. L., Janssen, I., & Gorber, S. C. (2010). Fitness of Canadian children and youth: results from the 2007–2009 Canadian Health Measures Survey. *Health Rep, 21*(1), 7-20.

Turk, V., Khattran, S., Kerry, S., Corney, R., & Painter, K. (2012). Reporting of Health Problems and Pain by Adults with An Intellectual Disability and by their carers. *Journal of Applied Research in Intellectual Disabilities, 25*(2), 155-165.

United Nations General Assembly. (2007). *Convention on the Rights of Persons with Disabilities and Optional Protocol*: UN.

Vicari, S. (2001). Implicit versus explicit memory function in children with Down and Williams syndrome. *Down Syndrome Research and Practice, 7*(1), 35-40.

Virk, S., Schwartz, T. L., Jindal, S., Nihalani, N., & Jones, N. (2004). Psychiatric medication induced obesity: an aetiologic review. *Obesity Reviews, 5*(3), 167-170. doi: 10.1111/j.1467-789X.2004.00141.x

Walls, H. L., Stevenson, C. E., Mannan, H. R., Abdullah, A., Reid, C. M., McNeil, J. J., & Peeters, A. (2011). Comparing Trends in BMI and Waist Circumference. *Obesity, 19*(1), 216-219. doi: 10.1038/oby.2010.149

Wang, Z., Patterson, C. M., & Hills, A. P. (2002). A comparison of self-reported and measured height, weight and BMI in Australian adolescents. *Australian and New Zealand Journal of Public Health, 26*(5), 473-478. doi: 10.1111/j.1467-842X.2002.tb00350.x

Waninge, A. (2010). *Measuring physical fitness in persons with severe/profound intellectual and multiple disabilities.* (Dissertation), University of Groningen, Groningen.

Wilson, D. N., & Haire, A. (1990). Health Care Screening For People With Mental Handicap Living In The Community. *BMJ: British Medical Journal, 301*(6765), 1379-1381.

World Health Organization. (2000). *Obesity: preventing and managing the global epidemic*: World Health Organization.

World Health Organization. (2001a). Classifications: International Classification of Functioning, disability, and health (ICF). from http://www.who.int/classifications/icf/en/

World Health Organization. (2001b). *International Classification of Functioning, Disability and Health*. Geneva: WHO.

World Health Organization. (2002). *Towards a common language for functioning, disability and health: ICF*: World Health Organisation.

World Health Organization. (2014). Obesity and overweight: Fact sheet. Retrieved Nov 17, 2013, from http://www.who.int/mediacentre/factsheets/fs311/en/

Yamaki, K. (2005). Body weight status among adults with intellectual disability in the community. *Journal Information, 43*(1).

Yoshitake, N., Okuda, M., Sasaki, S., Kunitsugu, I., & Hobara, T. (2012). Validity of self-reported body mass index of Japanese children and adolescents. *Pediatrics International, 54*(3), 397-401.

7 APPENDICES

Appendix 1: Certificate of approval from the University of Ontario Institute of Technology Research Ethics Board

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

Date: March 19th, 2014

To: Kristin Dobranowski (Student PI) and Robert Balogh (Supervisor)

From: Bill Goodman, REB Chair

REB File #: 13-099

Project Title: Is Measuring Best? Evaluating Reported Body Mass Index in Persons with Intellectual Disabilities

DECISION: APPROVED

START DATE: March 19th, 2014 EXPIRY: March 19th, 2015

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the above research proposal. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and the UOIT Research Ethics Policy and Procedures.

Please note that the (REB) requires that you adhere to the protocol as last reviewed and approved by the REB.

Always quote your REB file number on all future correspondence.

Please familiarize yourself with the following forms as they may become of use to you.

- **Change Request Form**: any changes or modifications (i.e. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or unexpected Events Form**: events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol. (I.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form**: must be completed when the research study has completed.
- **Renewal Request Form**: any project that exceeds the original approval period must receive approval by the REB through the completion of a Renewal Request Form before the expiry date has passed.

All Forms can be found at http://research.uoit.ca/faculty/policies-procedures-forms.php.

REB Chair Dr. Bill Goodman, FBIT bill.goodman@uoit.ca	Ethics and Compliance Officer compliance@uoit.ca

University of Ontario, Institute of Technology
2000 Simcoe Street North, Oshawa ON, L1H 7K4
PHONE: (905) 721-8668, ext. 3693

Appendix 2: Letter of approval from Special Olympics Ontario

Special Olympics
Ontario

28-Jan-14

To the Physiotherapy Foundation of Canada reviewers,

Special Olympics Ontario is pleased to support Dr. Robert Balogh's research project titled "Is Measuring Best? Evaluating Reported Body Mass Index in Persons with Intellectual Disabilities" to be submitted to the Physiotherapy Foundation of Canada for a Research Grant.

Special Olympics Ontario has organized sports and health oriented events for over 19,000 athletes with Intellectual Disabilities through its network of volunteer coaches, community agencies, healthcare professionals, school boards and parents. Past projects that Dr. Balogh has helped spearhead in partnership with Special Olympics Ontario include the successful facilitation of FUNfitness physical therapy screenings at various Special Olympics Healthy Athletes events across the province.

We hope to continue a partnership with Dr. Balogh and his research team as he ultimately applies for a research grant with the Physiotherapy Foundation of Canada.

Sincerely,

Glenn MacDonell
President & CEO
Special Olympics Ontario
(416) 447-8326 ext 225
glennm@specialolympicsontario.com

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Created by the Joseph P. Kennedy Jr. Foundation. Authorized and accredited by Special Olympics, Inc for the benefit of persons with intellectual disabilities.

Appendix 3: Special Olympics athlete recruitment script

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

SPECIAL OLYMPICS ONTARIO SPORTING EVENT: RECRUTIMENT SCRIPT

- Hello, my name is Kristin Dobranowski and I am doing my Masters in Health Sciences at the University of Ontario Institute of Technology in Oshawa, Ontario.
- Special Olympics Ontario has allowed me to be here today.
- My job is to research what people with intellectual disabilities think their height and weight is and see if it is the same as their height and weight when it is measured. And then I will compare their actual height and weight with their waist circumference.
- Do not worry if you do not know your exact height and weight, as many people do not get their exact height and weight right when they are asked.
- I would like to invite you to help me by being a part of my study.
- If you do not want to participate, you do not have to say yes, and you can continue on in your sporting event today. If you choose to withdraw from participating in my study, you will still receive a Subway gift card.
- Would you like to learn more about this opportunity?

Appendix 4: Special Olympics participant consent form

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

SPECIAL OLYMPICS ONTARIO ATHLETE CONSENT FORM (18+ & NO CAREGIVER)

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

You are invited to participate in a research study. I will read this form carefully aloud to you. There may be some words that you do not understand or things that you want me to explain more about. Please ask me at any time and I will take the time to explain. If you have questions you can ask me, Dr. Robert Balogh, your coach, your caregiver or anyone else you feel comfortable talking to.

Purpose and Procedure:
My job is to research about height and weight of individuals with intellectual disabilities, and determine how close they are at reporting their height and weight compared to when it is measured. Do not worry if you do not know your exact height and weight, as many people do not get their exact height and weight right when they are asked.

I will ask you and your caregiver your age, gender, current living situation, type of intellectual disability, height and weight, and your type of relationship with your caregiver (eg. Parent, Paid caregiver).

After these questions, another individual will measure your height, weight and waist circumference. This will take approximately 15 minutes in total.

Your reported height and weight will be compared with your actual height and weight.

Measurements that will be taken are:

- Height (you will stand with no shoes, and we will use a tall stick that you will stand in front of so your height can be measured)
- Weight (you will stand without shoes on a scale, so your weight can be recorded)
- Waist circumference (your waist will be measured with a tape, your shirt may have to be lifted up a little bit so the investigator can find your hip bone and measure your waist; this will take place behind a screen so it will be private)

Potential Benefits:
There are some potential benefits of participating in this research.

After your height and weight is measured, we will calculate your body mass index. We will then give you a paper with some examples and recommendations of different exercises and foods to eat.

1

The information found about how accurate you are at reporting your height and weight will help Special Olympics Ontario create new programs you may want to be a part of in the future.

Also, measuring your waist circumference will also help researchers like me better understand your health.

Potential Risk or Discomforts:

There is nothing dangerous or bad for you. We will ask you your height and weight and then another individual will measure your height, weight and waist circumference. If you feel uncomfortable answering the questions you do not have to answer or participate. To measure your waist circumference you may have to expose some of your skin around your stomach, so we can find your hip bones and measure your waist with a tape. The trainer will be available to help you, if you need assistance. If you are embarrassed or feel uncomfortable and want to stop that is okay. You do not have to participate if you do not want to. If you decide to stop or not participate in this study, then nothing will change, everything will stay the same as before. If you decide when you go home that you do not want to be a part of this study and you do not want your information used in research you can contact us and we will delete your information.

Storage of Data:

We will collect your data and change your name to a code, so we will not know what information if yours. It will be saved on a computer with a password and only Dr. Balogh and I will be able to see the data.
It will be stored for ten years, as I will need it to complete my project. When I no longer need the data it will be destroyed.

Confidentiality:

Remember we will not tell anyone anything you tell us here. Except if you tell us that someone is hurting you or you are going to seriously hurt yourself or someone else.

Compensation:

Once we ask you for your height and weight and measure you, you will be given a Subway gift card as a thank you for participating in my study.

Right to Withdraw:

Remember, you do not have to answer any questions that you do not want to answer. You can stop at any time. If you choose not to be a part of this study at any time you will still receive a Subway gift card.

Do you understand what is going to happen in this study?

- ○ **Do you consent to have your height and weight measured?**
- ○ **Do you consent to have your waist circumference measured?**

- ○ **Do you understand the benefits and risks of the study?**
- ○ **Do you understand that this information will not be shared with anyone else?**
- ○ **Do you understand that being a part of this study is up to you and you can stop at any time?**
- ○ **Have you asked any questions you may have and have they been answered?**
- ○ **Do you agree to freely provide verbal assent to participate in this study and that this collected data may be used for research?**

  - ○ **Yes**
  - ○ **No**

Would you like a copy of this information form for your records?

- ○ **Yes**
- ○ **No**

ATHLETE (18 + & NO CAREGIVER) VERBAL CONSENT FOR PARTICIPATION

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

- **This consent serves as documentation that the required elements of informed consent for the Special Olympics Ontario athlete have been presented orally by using the above verbal script.**
- **Verbal consent for the Special Olympics Ontario athlete to participate in this study has been obtained by the below investigator on the below date documenting their willingness to continue with the study and that the information may be used for research purposes.**

OR

Special Olympics Ontario athlete does not consent and does not want to take part in the study.___________(initialed)

I confirm that the athlete has given verbal consent freely.

______________________________	______________________________
(Name of athlete)	**(Date)**
	______________________________
	(Signature of Researcher)

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

4

ATHLETE (18+ & NO CAREGIVER) WRITTEN CONSENT FOR PARTICIPATION

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

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

....	....	....
Athlete Signature	**Print Name**	**Date**

____

(Signature of Researcher)

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

Appendix 5: Special Olympics participant assent form

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

SPECIAL OLYMPIC ATHLETE ASSENT FORM

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

You are invited to participate in a research study. I will read this form carefully aloud to you. There may be some words that you do not understand or things that you want me to explain more about. Please ask me at any time and I will take the time to explain. If you have questions you can ask me, Dr. Robert Balogh, your coach, your caregiver or anyone else you feel comfortable talking to.

Purpose and Procedure:
My job is to research about height and weight of individuals with intellectual disabilities, and determine how close they are at reporting their height and weight compared to when it is measured. Do not worry if you do not know your exact height and weight, as many people do not get their exact height and weight right when they are asked.

I will ask you and your caregiver your age, gender, current living situation, type of intellectual disability, height and weight, and your type of relationship with your caregiver (eg. Parent, Paid caregiver).

After these questions, another individual will measure your height, weight and waist circumference. This will take approximately 15 minutes in total.

Your reported height and weight will be compared with your actual height and weight.

Measurements that will be taken are:

Height (you will stand with no shoes, and we will use a tall stick that you will stand in front of so your height can be measured)

Weight (you will stand without shoes on a scale, so your weight can be recorded)

Waist circumference (your waist will be measured with a tape, your shirt may have to be lifted up a little bit so the investigator can find your hip bone and measure your waist; this will take place behind a screen so it will be private)

Potential Benefits:
There are some potential benefits of participating in this research.

1

After your height and weight is measured, we will calculate your body mass index. We will then give you a paper with some examples and recommendations of different exercises and foods to eat.

The information found about how accurate you are at reporting your height and weight will help Special Olympics Ontario create new programs you may want to be a part of in the future.

Also, measuring your waist circumference will also help researchers like me better understand your health.

Potential Risk or Discomforts:
There is nothing dangerous or bad for you. We will ask you your height and weight and then another individual will measure your height, weight, and waist circumference. If you feel uncomfortable answering the questions you do not have to answer or participate. To measure your waist circumference you may have to expose some of your skin around your stomach, so we can find your hip bones and measure your waist with a tape. The trainer will be available to help you, if you need assistance.

If you are embarrassed or feel uncomfortable and want to stop that is okay. You do not have to participate if you do not want to. If you decide to stop or not participate in this study, then nothing will change, everything will stay the same as before. If you decide when you go home that you do not want to be a part of this study and you do not want your information used in research you can contact us and we will delete your information.

Storage of Data:
We will collect your data and change your name to a code, so we will not know what information is yours. It will be saved on a computer with a password and only Dr. Balogh and myself will be able to see the data.
It will be stored for ten years, as I will need it to complete my project. When I no longer need the data it will be destroyed.

Confidentiality:
Remember we will not tell anyone anything you tell us here. Except if you tell us that someone is hurting you or you are going to seriously hurt yourself or someone else.

Compensation:
Once we ask you for your height and weight and measure you, you will be given a Subway gift card as a thank you for participating in my study.

Right to Withdraw:
Remember, you do not have to answer any questions that you do not want to answer. You can stop at any time. If you choose not to be a part of this study at any time you will still receive a Subway gift card.

Do you understand what is going to happen in this study?

- ○ **Do you assent to have your height and weight measured?**
- ○ **Do you assent to have your waist circumference measured?**

- ○ **Do you understand the benefits and risks of the study?**
- ○ **Do you understand that this information will not be shared with anyone else?**
- ○ **Do you understand that being a part of this study is up to you and you can stop at any time?**
- ○ **Have you asked any questions you may have and have they been answered?**
- ○ **Do you agree to freely provide verbal assent to participate in this study and that this collected data may be used for research?**
  - ○ **Yes**
  - ○ **No**

Would you like a copy of this information form for your records?

- ○ **Yes**
- ○ **No**

VERBAL ASSENT FOR PARTICIPATION

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

- **This consent serves as documentation that the required elements of informed assent for the Special Olympics Ontario athlete have been presented orally by using the above verbal script.**
- **Verbal assent from the Special Olympics Ontario athlete has been obtained by the below investigator on the below date documenting the Special Olympics Ontario athletes willingness to continue with the study and that the information may be used for research purposes.**

OR

Athlete does not assent and does not want to take part in the study.___________(initialed)

I confirm that the Special Olympics Ontario athlete has given verbal assent freely.

______________________________ (Name of athlete)　　**______________________________ (Date)**

______________________________ (Signature of Researcher)

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

Appendix 6: Special Olympics athlete's caregiver verbal or written consent

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

CAREGIVER CONSENT FORM

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

You and your Special Olympics Ontario athlete are invited to participate in a research study entitled Height and Weight of individuals with Intellectual Disabilities. This study (# REB 13-099) has been reviewed by the University of Ontario Institute of Technology Research Ethics Board and was originally approved on March 19th, 2014. I will read this form carefully, and feel free to ask any questions you might have of the Researcher or the Ethics and Compliance Officer. If you have any questions about your rights as a participant in this study, please contact the Ethics and Compliance Officer at 905 721 8668 ext. 3693 or compliance.uoit.ca.

Researcher(s):
Principal Investigator, Faculty Supervisor, Students etc(s):
Principal Investigator: Kristin Dobranowski
Faculty Supervisor: Dr. Robert Balogh
Departmental and institutional affiliation(s): University of Ontario Institute of Technology
Contact number(s)/email: Dr. Robert Balogh-905-721-8668 ext. 2602
External Funder/Sponsor: Special Olympics Ontario

Purpose and Procedure:
The purpose of this study is to determine how accurate a caregiver and/or Special Olympics Ontario athlete is at reporting their height and weight compared to their measured height and weight. To participate, I will explain this research and at the end I will ask if you consent for your athlete to participate in the study.

I will ask you, the caregiver, and your athlete, the athlete's age, gender, current living situation, type of intellectual disability, height and weight, and your type of relationship with the athlete (eg. Parent, Paid caregiver).

After these questions, another individual will measure their height, weight and waist circumference. This will take approximately 15 minutes in total.

The reported height and weight will be compared with the actual height and weight.

Measurements that will be taken are:

- Height (athletes will stand with no shoes, and we will use a stadiometer to measure height)
- Weight (athletes will stand without shoes on a scale, so their weight can be recorded)
- Waist circumference (athletes waist will be measured with a tape, their shirt may have to be lifted up so the investigator can find their hip bone and measure their waist; this will take place behind a screen so it will be private)

1

Potential Benefits:
There are some potential benefits of participating in this research.

After the height and weight is measured by the trained individuals, the body mass index of your athlete will be calculated, determining their BMI categorization. Following this, the athletes will be given a paper with some examples and recommendations of different exercises and foods to eat.

The information found about the accuracy of reported height and weight for individuals with an intellectual disability will benefit programs and policy development made by Special Olympics Ontario.

Also, measuring waist circumference will help researchers like me better understand your athlete's health.

Potential Risk or Discomforts:
There are very few risks to this research. The Special Olympics Ontario athlete may not understand all of the questions we ask, if they appear uncomfortable or ask to stop, we will stop right away. You or the athlete may not feel comfortable or embarrassed to share the weight and height of the Special Olympic athlete, or may be embarrassed if the reported height and weight values are different from the measured height and weight. It is important to remember that many people are often inaccurate when asked to provide their current height and weight. To measure waist circumference the athlete may have to expose some of their skin around their stomach, so we can find the top of their hip bones. The top of the hip bone is the guideline for where the tape should be placed to measure waist size. The trainer will be available to help the athlete find the top of their hip bone, if the athlete needs assistance. If you or the athlete feels embarrassed or uncomfortable you and the athlete may refuse to participate or withdraw from the study at any time, even after you have provided consent. You can withdraw up to two months after the study, at that time all information collected will be immediately destroyed. After two months, the information will have been analyzed for research purposes and will not be able to be deleted.

Storage of Data:
Each persons collected data will become associated with a code. If you decide to withdraw, we will be able to determine what your code is and delete your collected data. The data will be saved on a password protected by computer and only myself and Dr. Robert Balogh will have access to the information. It will be stored for ten years, as I will need it to complete my research project and it may be used for secondary purposes, such as if I decide to write another paper. When the data is no longer required it will be appropriately destroyed.

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 I and Dr. Robert Balogh will have access to the list of names of participants. The information you share will be combined with other participants' information, and **you or the Special Olympics Ontario athlete will never be identified** in any way if/when the results of this study are published.

Compensation:
Once the data has been collected each Special Olympics Ontario athlete will be given a Subway gift card as a thank you for participating in my study.

Right to Withdraw:
Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team. As stated, you may withdraw at any time without any consequences. If you withdraw within two months after this study, any data you have provided will be removed from the data and you need not offer any reason for making this request. After two months, the data will have been analyzed for publishing. It is very difficult to withdraw results once they have been analyzed for publishing.
You will be given information that is relevant to your decision to continue or withdraw from participation. If at any point during and after the study you and your athlete would like to withdraw from the study, the athlete will still receive a Subway gift card.

Participant Concerns and Reporting:
This research project has been approved by the University of Ontario Institute of Technology Research Ethics Board on (insert date). If you have any questions concerning the research study, or experience any discomfort related to the study please contact the researcher(s) at 905-721-8668 ext. 2602. Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Compliance Office (905 721 8668 ext 3693).

Debriefing and Dissemination of Results:
After the data has been collected, we will calculate the Body Mass Index of the Special Olympics Ontario athletes and share it with you and the athlete, and then we will give the athlete a paper with recommendations for exercises and nutritious food.

- ○ **Do you understand the purpose and procedures of this study?**
    - ○ **Do you consent to have your athlete's height and weight measured?**
    - ○ **Do you consent to have your athlete's waist circumference measured?**
- ○ **Do you understand the benefits and risks of the study?**
- ○ **Do you understand how the data will be stored and that it will be confidential?**
- ○ **Do you understand that participation is voluntary and you can withdraw from this study at any time, up to two months after this date?**
- ○ **Have you asked any questions you may have and have they been answered?**
- ○ **Do you agree to freely provide verbal consent for the Special Olympics Ontario athlete to participate in this study and that this collected data may be used for research?**
    - ○ **Yes**
    - ○ **No**
- ○ **If necessary: Do you agree to freely provide written consent for the Special Olympics Ontario athlete to participate in this study and that this collected data may be used for research?**
    - ○ **Yes**
    - ○ **No**

Would you like a copy of this information form for your records?

- ○ **Yes**
- ○ **No**

CAREGIVER VERBAL CONSENT FOR PARTICIPATION

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

- **This consent serves as documentation that the required elements of informed consent for the Special Olympics Ontario athlete by their caregiver have been presented orally by using the above verbal script.**
- **Verbal consent for the Special Olympics Ontario athlete by their caregiver to participate in this study has been obtained by the below investigator on the below date documenting their willingness to continue with the study and that the information may be used for research purposes.**

OR

Caregiver does not consent and does not want athlete to take part in the study.___________(initialed)

I confirm that the caregiver has given verbal consent freely.

(Name of athlete)	**(Name of caregiver)**	**(Date)**
	(Signature of Researcher)	

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

CAREGIVER WRITTEN CONSENT FOR PARTICIPATION

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

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

....
Athlete Name

....
Caregiver Signature **Print Name** **Date**

____
(Signature of Researcher)

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

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Appendix 7: Special Olympics athlete information form (take-home)

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

SPECIAL OLYMPICS ATHLETE INFORMATION FORM

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

You have been invited to participate in a research study about the height and weight of individuals with intellectual disabilities. This study (# REB 13-099) has been reviewed by the University of Ontario Institute of Technology Research Ethics Board and was originally approved on March 19th, 2014. Feel free to ask any questions you might have of the Researcher or the Ethics and Compliance Officer. If you have any questions about your rights as a participant in this study, please contact the Ethics and Compliance Officer at 905 721 8668 ext. 3693 or compliance.uoit.ca.

Researcher(s):
Principal Investigator, Faculty Supervisor, Students etc(s):
Principal Investigator: Kristin Dobranowski
Faculty Supervisor: Dr. Robert Balogh
Departmental and institutional affiliation(s): University of Ontario Institute of Technology
Contact number(s)/email: Dr. Robert Balogh-905-721-8668 ext. 2602
External Funder/Sponsor: Special Olympics Ontario

Purpose and Procedure:
My job is to research about height and weight of individuals with intellectual disabilities, and determine how close they are at reporting their height and weight compared to when it is measured. Do not worry if you do not know your exact height and weight, as many people do not get their exact height and weight right when they are asked.

I will ask you and your caregiver your age, gender, current living situation, type of intellectual disability, height and weight, and your type of relationship with your caregiver (eg. Parent, Paid caregiver).

After these questions, another individual will measure your height, weight and waist circumference. This will take approximately 15 minutes in total.

Your reported height and weight will be compared with your actual height and weight.

Measurements that will be taken are:

- Height (you will stand with no shoes, and we will use a tall stick that you will stand in front of so your height can be measured)
- Weight (you will stand without shoes on a scale, so your weight can be recorded)

- Waist circumference (your waist will be measured with a tape, your shirt may have to be lifted up a little bit so the investigator can find your hip bone and measure your waist; this will take place behind a screen so it will be private)

Potential Benefits:

There are some potential benefits of participating in this research.
After your height and weight is measured, we will calculate your body mass index. We will then give you a paper with some examples and recommendations of different exercises and foods to eat.

The information found about how accurate you are at reporting your height and weight will help Special Olympics Ontario create new programs you may want to be a part of in the future. Also, measuring your waist circumference will also help researchers like me better understand your health.

Potential Risk or Discomforts:

There is nothing dangerous or bad for you. We will ask you your height and weight and then another individual will measure your height, weight and waist circumference. If you feel uncomfortable answering the questions you do not have to answer or participate. To measure your waist circumference you may have to expose some of your skin around your stomach, so we can find your hip bones and measure your waist with a tape. The trainer will be available to help you, if you need assistance. If you are embarrassed or feel uncomfortable and want to stop that is okay. You do not have to participate if you do not want to. If you decide to stop or not participate in this study, then nothing will change, everything will stay the same as before. If you decide when you go home that you do not want to be a part of this study and you do not want your information used in research you can contact us and we will delete your information.

Storage of Data:

We will collect your data and change your name to a code, so we will not know what information if yours. It will be saved on a computer with a password and only Dr. Balogh and I will be able to see the data.
It will be stored for ten years, as I will need it to complete my project. When I no longer need the data it will be destroyed.

Confidentiality:

Remember we will not tell anyone anything you tell us here. Except if you tell us that someone is hurting you or you are going to seriously hurt yourself or someone else.

Compensation:

Once we ask you for your height and weight and measured you, you will be given a Subway gift card as a thank you for participating in my study.

Right to Withdraw:

Remember, you do not have to answer any questions that you do not want to answer. You can stop at any time. If you choose not to be a part of this study at any time you will still receive a Subway gift card.

2

Appendix 8: Special Olympics caregiver information form (take-home)

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

CAREGIVER INFORMATION FORM

Title of Research Study: Is Measuring Best? Evaluating Reported Body Mass Index in Special Olympics Athletes

You and your Special Olympics Ontario athlete have been invited to participate in a research study about the height and weight of individuals with intellectual disabilities. This study (#REB 13-099) has been reviewed by the University of Ontario Institute of Technology Research Ethics Board and was originally approved on March 19th, 2014. Feel free to ask any questions you might have of the Researcher or the Ethics and Compliance Officer. If you have any questions about your rights as a participant in this study, please contact the Ethics and Compliance Officer at 905 721 8668 ext. 3693 or compliance.uoit.ca.

Researcher(s):
Principal Investigator, Faculty Supervisor, Students etc(s):
Principal Investigator: Kristin Dobranowski
Faculty Supervisor: Dr. Robert Balogh
Departmental and institutional affiliation(s): University of Ontario Institute of Technology
Contact number(s)/email: Dr. Robert Balogh-905-721-8668 ext. 2602
External Funder/Sponsor: Special Olympics Ontario

Purpose and Procedure:
The purpose of this study is to determine how accurate a caregiver and/or Special Olympics Ontario athlete is at reporting their height and weight compared to their measured height and weight. To participate, I will explain this research and at the end I will ask if you consent for your athlete to participate in the study.

I will ask you, the caregiver, and your athlete, the athlete's age, gender, current living situation, type of intellectual disability, height and weight, and your type of relationship with the athlete (eg. Parent, Paid caregiver).

After these questions, another individual will measure their height, weight and waist circumference. This will take approximately 15 minutes in total.

The reported height and weight will be compared with the actual height and weight.

Measurements that will be taken are:

- Height (athletes will stand with no shoes, and we will use a stadiometer to measure height)
- Weight (athletes will stand without shoes on a scale, so their weight can be recorded)
- Waist circumference (athletes waist will be measured with a tape, their shirt may have to be lifted up so the investigator can find their hip bone and measure their waist; this will take place behind a screen so it will be private)

1

Potential Benefits:
There are some potential benefits of participating in this research.

After the height and weight is measured by the trained individuals, the body mass index of your athlete will be calculated, determining their BMI categorization. Following this, the athletes will be given a paper with some examples and recommendations of different exercises and foods to eat.

The information found about the accuracy of reported height and weight for individuals with an intellectual disability will benefit programs and policy development made by Special Olympics Ontario.

Also, measuring waist circumference will help researchers like me better understand your athlete's health.

Potential Risk or Discomforts:
There are very few risks to this research. The Special Olympics Ontario athlete may not understand all of the questions we ask, if they appear uncomfortable or ask to stop, we will stop right away. You or the athlete may not feel comfortable or embarrassed to share the weight and height of the Special Olympic athlete, or may be embarrassed if the reported height and weight values are different from the measured height and weight. It is important to remember that many people are often inaccurate when asked to provide their current height and weight. To measure waist circumference the athlete may have to expose some of their skin around their stomach, so we can find the top of their hip bones. The top of the hip bone is the guideline for where the tape should be placed to measure waist size. The trainer will be available to help the athlete find the top of their hip bone, if the athlete needs assistance. If you or the athlete feels embarrassed or uncomfortable you and the athlete may refuse to participate or withdraw from the study at any time, even after you have provided consent. You can withdraw up to two months after the study, at that time all information collected will be immediately destroyed. After two months, the information will have been analyzed for research purposes and will not be able to be deleted.

Storage of Data:
Each persons collected data will become associated with a code. If you decide to withdraw, we will be able to determine what your code is and delete your collected data. The data will be saved on a password protected by computer and only myself and Dr. Robert Balogh will have access to the information. It will be stored for ten years, as I will need it to complete my research project and it may be used for secondary purposes, such as if I decide to write another paper. When the data is no longer required it will be appropriately destroyed.

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 I and Dr. Robert Balogh will have access to the list of names of participants. The information you share will be combined with other participants' information, and **you or the Special Olympics Ontario athlete will never be identified** in any way if/when the results of this study are published.

Compensation:
Once the data has been collected each Special Olympics Ontario athlete will be given a Subway gift card as a thank you for participating in my study.

Right to Withdraw:
Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team. As stated, you may withdraw at any time without any consequences. If you withdraw within two months after this study, any data you have provided will be removed from the data and you need not offer any reason for making this request. After two months, the data will have been analyzed for publishing. It is very difficult to withdraw results once they have been analyzed for publishing. You will be given information that is relevant to your decision to continue or withdraw from participation. If at any point during and after the study you and your athlete would like to withdraw from the study, the athlete will still receive a Subway gift card.

Participant Concerns and Reporting:
This research project has been approved by the University of Ontario Institute of Technology Research Ethics Board on (insert date). If you have any questions concerning the research study, or experience any discomfort related to the study please contact the researcher(s) at 905-721-8668 ext. 2602. Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Compliance Office (905 721 8668 ext. 3693).

Debriefing and Dissemination of Results:
After the data has been collected, we will calculate the Body Mass Index of the Special Olympics Ontario athletes and share it with you and the athlete, and then we will give the athlete a paper with recommendations for exercises and nutritious food.

Appendix 9: Event Questionnaire

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
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O Male O Female	D.O.B: ____________ OR Age: ________ Years O Do not know	Non-verbal? O Yes O No

What is the cause of the intellectual disability: O Down Syndrome O Autism Spectrum Disorder (ASD) O Prader Willi Syndome O Fragile X O PKU O Cerebral Palsy O Fetal Alcohol Spectrum Disorder O Psychiatric Disorder o Specify: ________________ O Other: ________________ O Unknown	What is your living situation: O At family home with parents O At family home with grandparents O At family home with other: __________ O In group home O In foster home O Independent living O Alone O With roommate(s) O Other: __________________________

Address: ____
O Do not know

Any injuries or conditions that may affect testing results:
____

Is caregiver present: O Yes O No	Type of relationship of caregiver with athlete: O Parent O Grandparent O Paid caregiver O Volunteer caregiver O Sibling O Other: ______________________________

What is the level of intellectual disability:

- O Mild (Ex. Difficulties learning how to read and write; personal care independent (help sometimes needed); adult can live independently with support)
- O Moderate (Ex. Learning to read occurs slowly and limited compared to peers; some personal care independent with extended teaching and reminders; ongoing support needed in daily life (daily schedules))

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○ Severe (Ex. Little understanding of written language; spoken language is limited; requires support for all daily life activities)
○ Profound (Ex. Little understanding of speech; expresses wishes through non-verbal communication; dependent on others)
○ Don't know
○ Not applicable (prefers not to answer)

HEIGHT AND WEIGHT

Reported: Height and Weight	**Athlete** **Height ________(cm) Weight ________(kg)** **________(inches) ________(lbs)** ○ **Don't know** **Did athlete provide biologically implausible option?** ○ **No** ○ **Yes:____** **Ask question again (do you know your height in cm or feet and inches (like 5 ft and 5 inches, and 150 lbs). Was answer plausible?** ○ **No- nothing recorded** ○ **Yes (recorded above)** **Notes:** ____ ____
	Caregiver **Height ________(cm) Weight ________(kg)** **________(inches) ________(lbs)** ○ **Don't know** **Notes:** ____ ____
	Consensus (if needed): **Height: ________(cm) Weight ________(kg)** **________(inches) ________(lbs)** **Notes:** ____ ______ ____ __________

Measured: Height, Weight And Waist Circumference	**Athlete:** **Height ________(cm)** **Weight ________ (kg)** **________(inches)** **________(lbs)** **Waist circumference: ______________ (cm)** **Notes:** ____________________ ____________________ ____________________

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Appendix 10: Special Olympics verbal thank-you script

UNIVERSITY OF ONTARIO
INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

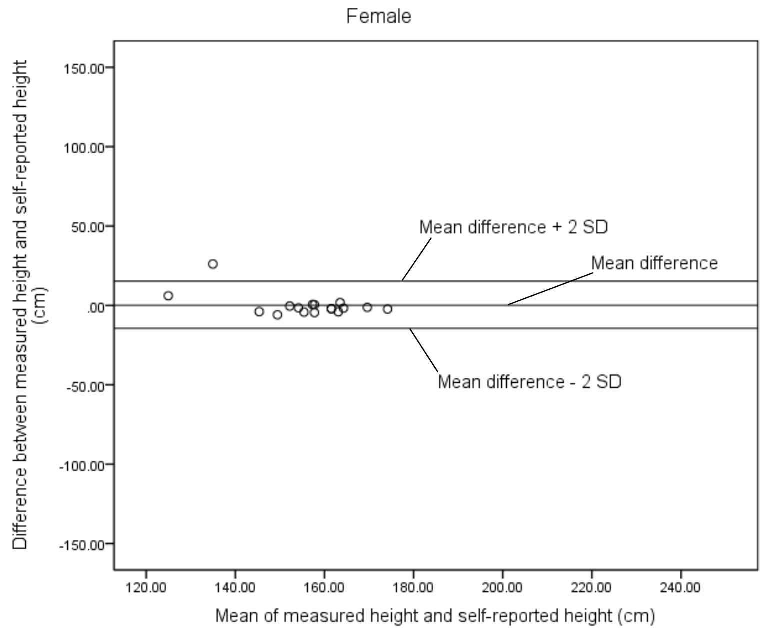
VERBAL THANK YOU SCRIPT

Thank you all for participating in my study. I am thankful to have met all of you and for all of your co-operation, it is greatly appreciated, everyone did great!
I hope that everyone had a good day today and I wish you all the best in your upcoming sporting events.

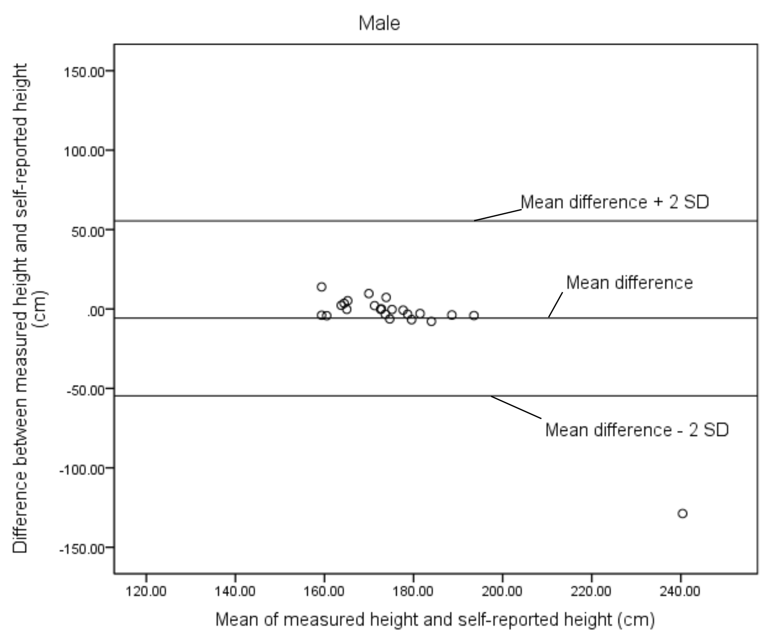
(Ctrl)

Appendix 11. Bland and Altman plots of measured versus self-reported height, for a) females and b) males

a)

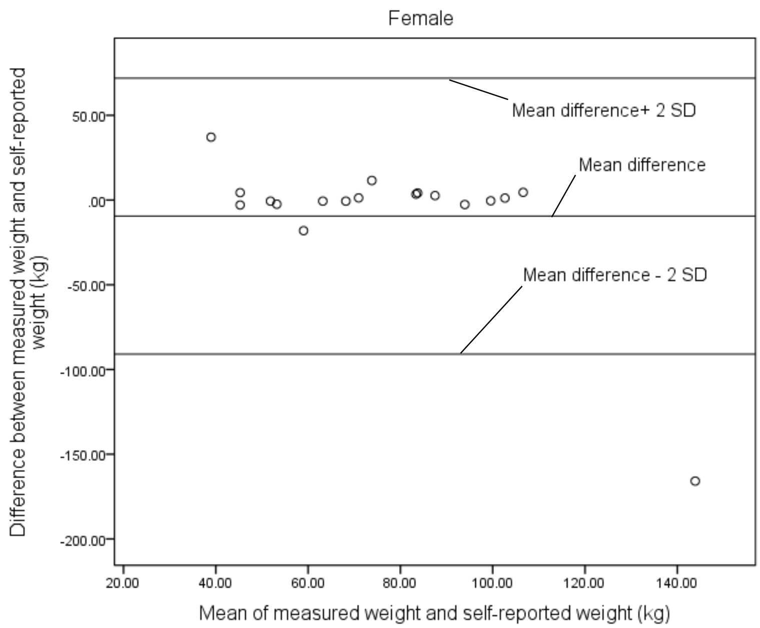


b)

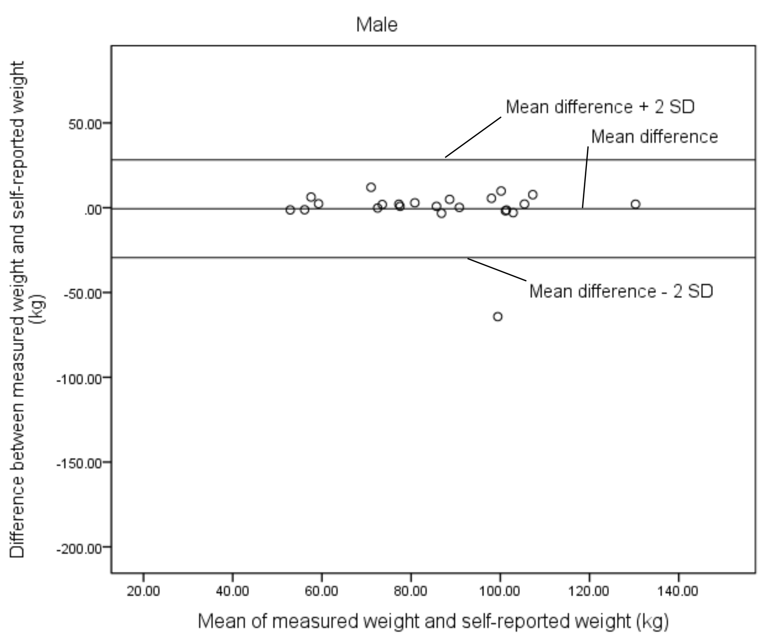


Appendix 12. Bland and Altman plots of measured versus self-reported weight for a) females and b) males

a)

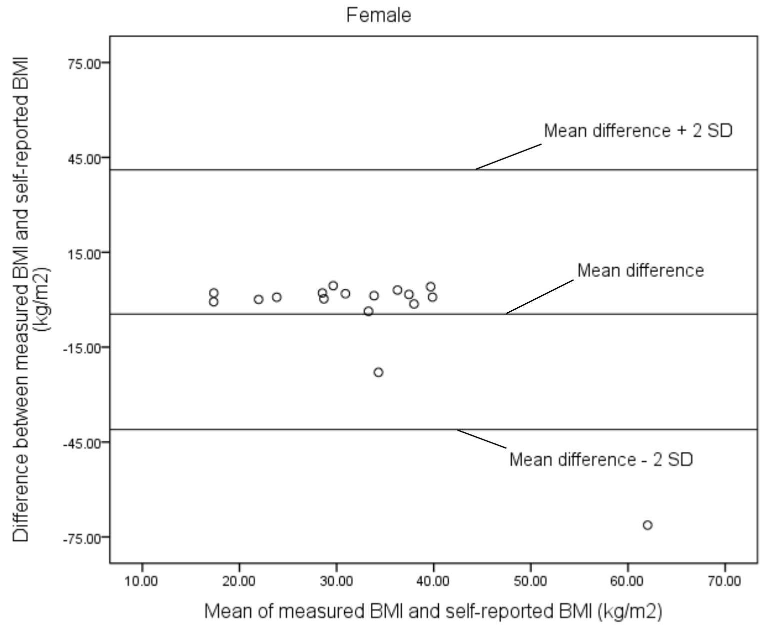


b)

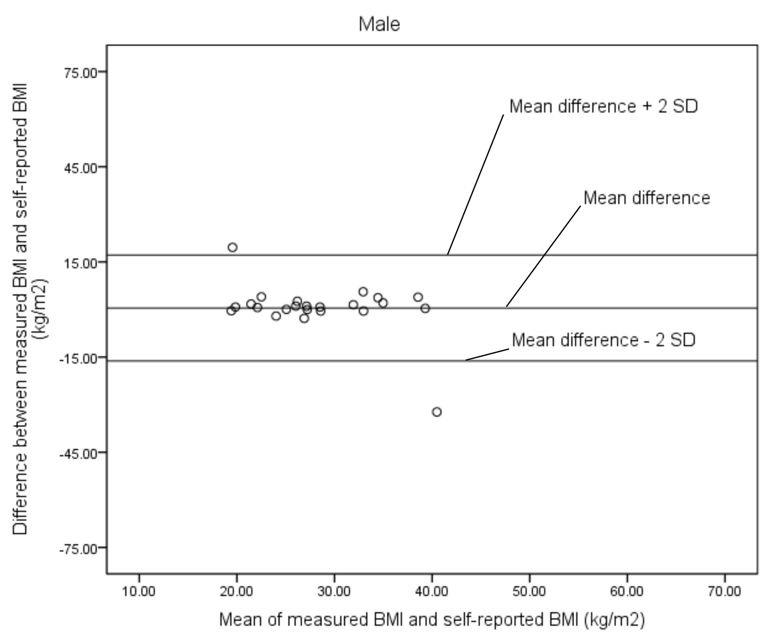


Appendix 13. Bland and Altman plots of measured versus self-reported height and weight for BMI calculation, for a) females and b) males

a)



b)



Appendix 14: Categorization of adults with ID without an outlier, in different BMI categories according to the World Health Organization (WHO) cutoffs, and differences between measured and self-reported proportion in each category

	Measured		Self-reported		Difference[a]		p^b
	%	(n)	%	(n)	%	95% CI	
Females (n=16)							
Underweight	12.5	2	12.5	2	0		1.00
Normal weight	18.8	3	12.5	2	6.3	-5.61 - 18.1	1.00
Overweight/Obese	68.7	11	75.0	12	-6.3	-18.1 - 5.61	1.00
Total (n=39)							
Underweight	5.1	2	7.7	3	-2.6	-7.52 - 2.39	1.00
Normal weight	25.6	10	20.5	8	5.1	-4.79 - 15.1	0.63
Overweight/Obese	69.2	27	71.8	28	-2.6	-13.8 - 8.65	1.00

[a] Difference in proportion of underweight, normal weight, overweight/obesity were obtained using the Agresti method for comparing dependent proportions
[b] According to McNemar's test

Appendix 15: The number and proportion of adults with ID without an outlier, classified in different BMI categories based on self-reported and measured height and weight in females and the total sample

		BMI-category based on Measured BMI						Total	
		Underweight		Normal weight		Overweight/obese		n (%)	
		n	(%)	n	(%)	n	(%)		
	Females (n=16)								
BMI-category based on self-reported BMI	Underweight	2	12.5	0	0.0	0	0.0	2	12.5
	Normal weight	0	0.0	2	12.5	0	0.0	2	12.5
	Overweight/ obese	0	0.0	1	6.3	11	69.0	12	75.3
	Total	2	12.5	3	18.8	11	69.0	16	100
	Total (n=39)								
BMI-category based on self-reported BMI	Underweight	2	5.1	0	0.0	1	2.6	3	7.7
	Normal weight	0	0.0	7	17.9	1	2.6	8	20.5
	Overweight/ obese	0	0.0	3	7.7	25	64.1	28	71.8
	Total	2	5.1	10	25.6	27	69.3	39	100

Values in highlighted boxes represent accurate classification by self-report

Appendix 16: Diagnostic performance of self-reported height and weight without outliers for determining overweight/obesity in females and the total sample

	Sensitivity		Specificity		PPV[a]		NPV[b]		Kappa statistic
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%
Females (n=16)									
BMI Category Overweight/ Obese	100.0	67.8 - 29.9	80.0	29.9 - 98.9	91.7	59.8 - 99.6	100.0	39.6 - 100.0	0.846
Total (n=39)									
BMI Category Overweight/ Obese	92.6	74.2 - 98.7	75.0	42.8 - 93.3	89.3	70.6 - 97.2	81.8	47.8 - 96.8	0.692

[a] Positive Predictive Value, [b] Negative Predictive Value

Appendix 17: Categorization of adults with mild ID, without an outlier, in different BMI categories according to the World Health Organization (WHO) cutoffs, and differences between measured and self-reported proportion in each category

	Measured		Self-reported		Difference[a]		p^b
	%	(n)	%	(n)	%	95% CI	
Mild ID (n=34)							
Underweight	5.9	2	8.8	3	-2.9	-8.62 - 2.74	1.00
Normal weight	26.5	9	20.6	7	5.9	-5.48 - 1.72	0.63
Overweight/Obese	67.7	23	70.6	24	-2.9	-15.8 - 9.91	1.00

[a] Difference in proportion of underweight, normal weight, overweight/obesity were obtained using the Agresti method for comparing dependent proportions
[b]According to McNemar's test

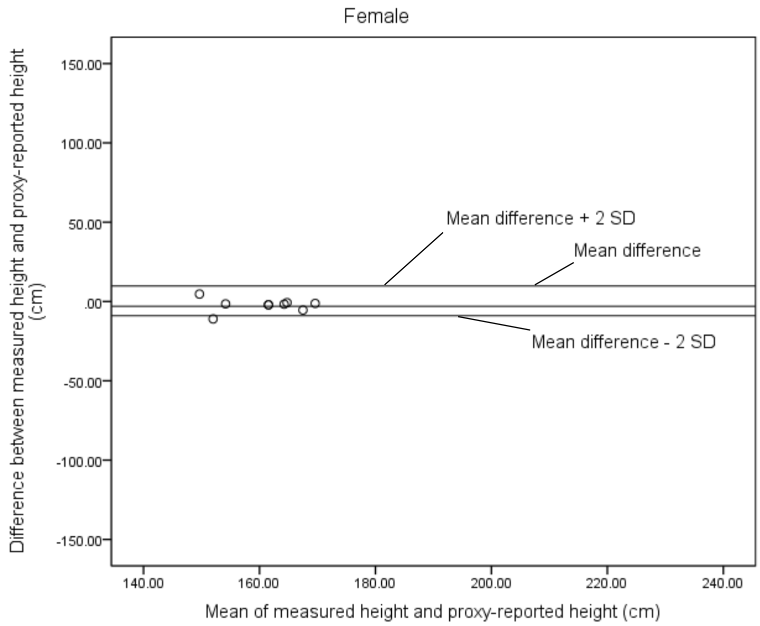
Appendix 18: Diagnostic performance of self-reported height and weight without outliers for determining overweight/obesity in adults with mild ID

	Sensitivity		Specificity		PPV[a]		NPV[b]		Kappa statistic
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%
Mild ID (n=34)									
BMI Category									
Overweight/ Obesity	91.3	70.5 - 98.5	72.7	39.3 - 92.7	87.5	66.5 - 96.7	80.0	44.2 - 96.5	0.656

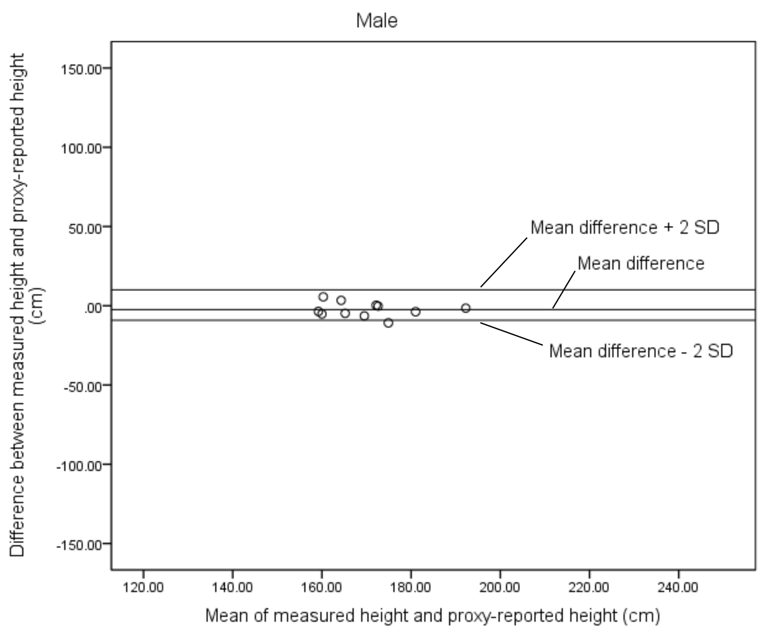
[a] Positive Predictive Value, [b] Negative Predictive Value

Appendix 19: Bland and Altman plots of measured versus proxy-reported height for a) females and b) males

a)

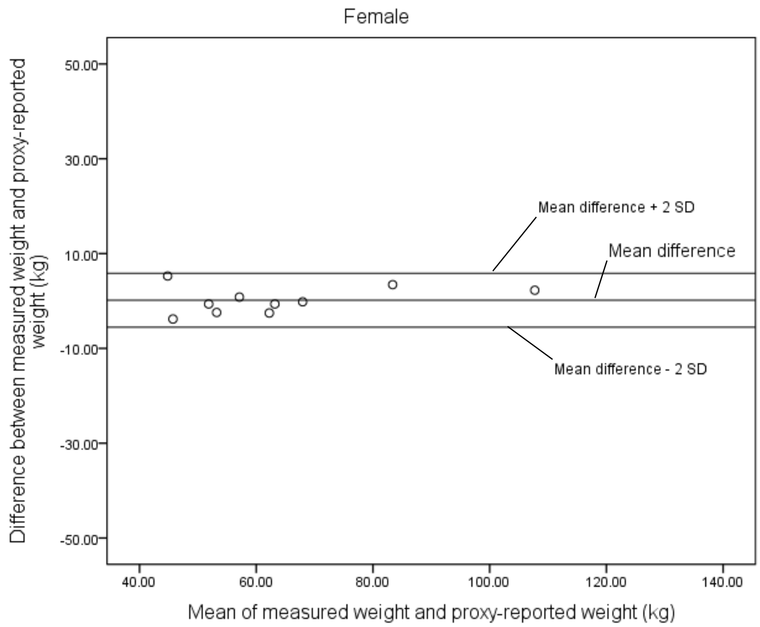


b)

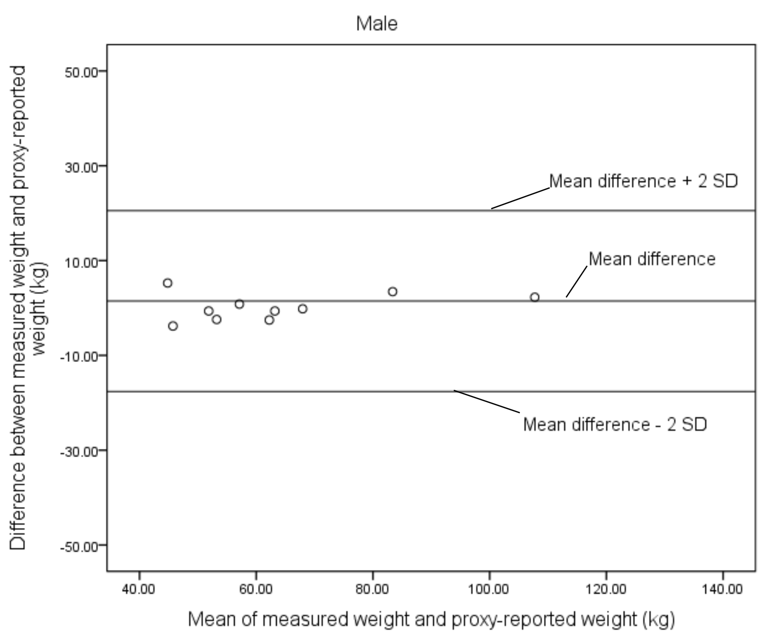


Appendix 20: Bland and Altman plots of measured versus proxy-reported weight for a) females and b) males

a)

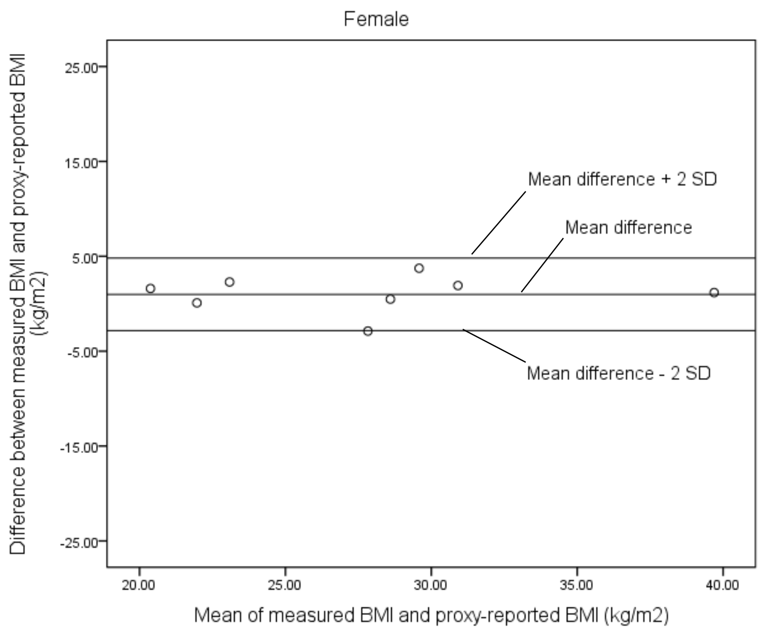


b)

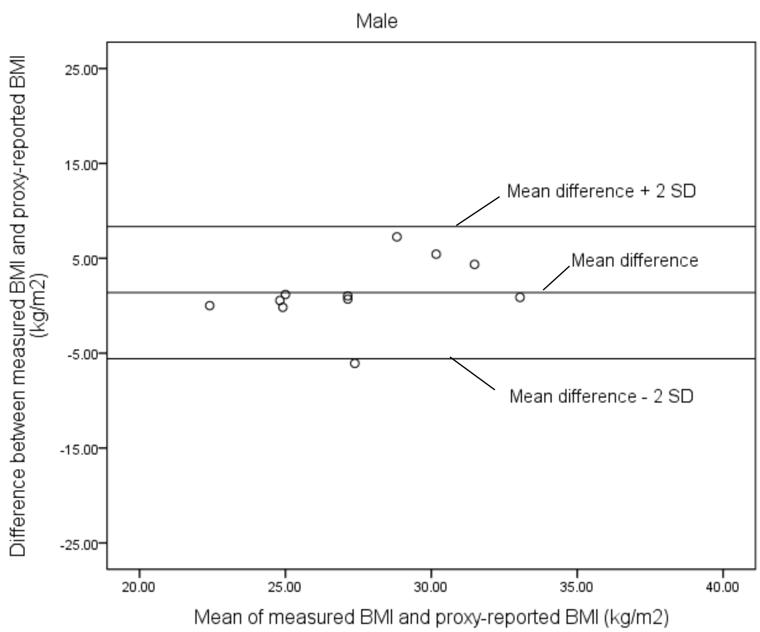


Appendix 21: Bland and Altman plots of measured versus proxy-reported height and weight for BMI calculation, for a) females and b) males

a)



b)



Appendix 22: Manuscript 1 and 2 recommendations summarized in flow-chart style