A comparison of physical activity, physical fitness levels, BMI, and blood pressure of adults with intellectual disability, who do and do not take part in Special Olympics Ireland programmes

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Honesty Statement

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Abbreviations used

AAIDD American Association of Intellectual and Developmental Disabilities
ACSM American College of Sports Medicine
AHA American Heart Association
ANOVA Analysis Of Variance
BMI Body Mass Index
BP Blood Pressure
COPD Chronic Obstruction Pulmonary Disease
CVD Cardiovascular disease
DLW Doubly labelled water
DS Down syndrome
ID Intellectual Disability
IPAQ International Physical Activity Questionnaire
MVPA Moderate to vigorous physical activity
NDA National Disability Authority
NHANES National Health and Nutrition Examination Survey
NHS National Health Service (UK)
NHSCT Northern Health and Social Care Trust
NIDD National Intellectual Disability Database
PA Physical Activity
SLÁN Survey of Lifestyle, Attitudes and Nutrition
SO Special Olympics
SOI Special Olympics Ireland
STEPS STEPwise approach to Surveillance
TILDA The Irish Longitudinal Study on Ageing
$V0^2$ MAX Maximal volume of oxygen consumption
6MWT Six minute walk test

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Abstract

Background: It has been reported in the literature that people with an intellectual disability (ID) are less physically active, live more sedentary lives, have lower fitness levels and are more likely to be overweight or obese than the general population. Nine thousand people with ID are participating in Special Olympics Ireland (SOI). To date, no evidence exists on the impact of SOI participation on physical activity (PA) and physical fitness levels of adults with ID's in Ireland.

Methods: Adults with ID (16-64 years) were recruited from 4 ID services and SOI clubs throughout Ireland (n=146, male 85, female 61). Both SOI participants and non SOI participants were invited to participate. Physical measures included waist circumference, height, weight, blood pressure, heart rate and the Six Minute Walking Test. Self-report questionnaires were administered to study participants to gather data on PA levels. To get an objective measure of PA, participants were asked to wear an Actigraph (GT3X) accelerometer for seven consecutive days.

Results: Self-report data suggests SOI participants accumulated significantly more mean minutes moderate to vigorous physical activity (MVPA) daily than non-SOI participants ($p = .002$). SOI participants also recorded more minutes of accelerometer measured MVPA on average daily than non-SOI participants, however differences were not statistically significant. Significantly greater distances were walked in the Six Minute Walk test by SOI participants compared to non-SOI participants ($p = .000$), and those in SOI had a significantly more positive health profile score than those not in SOI ($p = .013$).

Conclusion: Participants in SOI accumulated significantly more minutes of MVPA per day, had higher fitness levels, and more positive health profile scores than non-SOI participants. SOI has the potential to make a positive difference to people's physical health and subsequently their overall health and wellbeing.

KeyWords: Physical activity, Intellectual Disability, Special Olympics Ireland

Introduction

Intellectual disability (ID) has been defined by the World Health Organisation Regional Office for Europe as a significantly reduced ability to understand complex or new information and to apply new learned skills. It typically occurs before adulthood and usually has a lasting effect on development, this result in a reduced ability to cope independently (WHO 2015).

Regular participation in physical activity (PA) is widely acknowledged as being important for primary and secondary prevention of an array of conditions including several chronic diseases, such as obesity, coronary heart disease, hypertension, Type 2 diabetes, osteoporosis, depression and colon cancer (Marshall et al. 2003; Thompson et al. 2003; Bonaiuti et al. 2002; Blumenthal et al. 1999 and Evans, 1999). It can also reduce the risk of premature death (Warburton, Crystal and Bredin 2006). This is particularly beneficial to those with ID who are at a greater risk of co-morbidities of respiratory disease, cardiovascular disease (CVD) and cancer (Prasher and Janicki 2002). Macera, Hootman and Sniezek (2003) found that inactive people are twice as likely to develop/die from chronic heart disease as active people. Rippe et al. (1988) highlights even if a person was to perform activities of low- moderate intensity, like walking for pleasure, dancing or yard work on a daily basis, they would reap long term health benefits and reduce the risk of CVD. People with disabilities who are more physically active tend to visit doctors less and have fewer medical complications (Hannon, Fitzsimon and Kelleher 2006).

The psychological benefits attributed to PA are just as significant as the physical benefits to the human body. Andrews (2005) reveals that PA increases well-being by increasing pride in physical accomplishments, improving body image and promoting more self-confidence. Specifically for persons with disabilities, PA focuses on one's physical abilities more so than their physical or mobility issues (Weiss et al. 2003). A report by the US Department of Health and Human Sciences (2008) concluded that people with ID reap the same benefits when it comes to PA as the general population.

Guidelines for PA drawn up by the American College of Sports Medicine (2011) specify recommendations for all members of the population including people with disabilities. All adults (aged 18-65) should accumulate at least 30-60 minutes of moderate-intensity aerobic activity 5 days per week or engage in 20- 60 minutes of vigorous activity 3 days per week. It is further stipulated that activity must be at least 10 minutes in duration to count towards daily goals, and that a combination of moderate and vigorous physical activity (MVPA) is acceptable. The National PA Guidelines for Ireland reinforce the recommendation of a minimum of 30 minutes of MVPA per day for adults to garner health benefits (Department of Health and Children and the Health Executive 2009).

It has been widely reported in the literature that the ID population is less physically active and live more sedentary lives compared with the general population (Hilgenkamp, van Wijck and Evenhuis 2012b, Frey, Stanish and Temple 2008). The proportion of people with ID who are overweight or obese also appears to be higher compared with the general population (Marshall et al. 2003; Prasher 1995 and Martin et al. 1997).

A scarcity of studies have explored PA patterns and the barriers/motivators affecting sedentary behaviours in adults with ID, and particularly so in an Irish population. While the SLÁN 2007 study (Ward 2009) found that a high proportion of the Irish population do not meet the minimum PA guideline, a report by (Hannon, Fitzsimon and Kelleher (2006) carried out a secondary data analysis of the 1998 and 2002 SLÁN data, revealed that people with disabilities were even less likely to comply with the known minimal PA recommendations. The Hannon, Fitzsimon and Kelleher (2006) report showed that 35% of people with a disability reported no PA of at least moderate intensity per week, compared to just 10% of the general population. People with physical and learning disabilities were also found to be less likely to undergo PA of any type including leisure, housework or work when compared to those reporting no disability (Hannon, Fitzsimon and Kelleher 2006). The TILDA (The Irish Longitudinal Study on Ageing) report on people with disability in Ireland further highlighted that 77.3% of Irish adults with ID over the age of 40 years, were considered overweight or obese (McCarron et al. 2014).

Issues with low levels of PA are not exclusive to the ID population in Ireland, with research showing that people with ID are less physically active than the general population worldwide (Stanish, Temple and Frey 2006; Robertson et al. 2000; Temple 2007). In a UK study, Messent, Cooke and Long (1999) examined a seven day PA profile revealing that 22 of the 24 participants were significantly below the Department of Health minimum PA guidelines, demonstrated high levels of obesity and also scored lower levels of cardiorespiratory fitness levels compared to the general population. It has also been shown however that increased PA levels benefit people with ID, and that targeted strategies can be successful in helping those with ID achieve these benefits. Wu et al. (2010) evaluated a 6 month physical fitness program on people with ID living in a disability institution in North Taiwan. Post intervention scores showed statistically significant decreases in individual's weight, BMI score and BMI category after the 6 month intervention.

A case study carried out by Escobar et al. (2013) examined the impact of an aquatic PA programme on the mobility and quality of life of an individual with both severe intellectual and physical disabilities. The study was carried out over a 16 month period with 3 sessions per week for 30-40 minutes per session. Findings revealed that the programme improved activities of daily living including sit to stand, stair climbing, walking speed and walking distance.

Bartlo and Klein (2011) ran a systemic review of the literature on the PA benefits and needs for adults with ID. Within this review they found compelling evidence to suggest that PA is extremely important in creating improvements in a number of aspects of a person's physical state.

Rimmer et al. (2004) examined peak VO^2 performance and strength of adults (mean age 39.4 years) with mild to moderate Down Syndrome (DS) (n=52). Results revealed that after completing a 12 week intervention consisting of cardiovascular training followed by upper and lower body strength training, participants saw a significant improvement in cardiovascular functioning ($p<0.01$) and upper and lower body strength ($p<0.0001$). Carmeli et al (2005) conducted a randomised controlled trial on (n=22) adults with mild ID (age 60.9 years ± 3.3). The intervention consisted of both balance and strength activities

carried out 3 days a week over a 6 month period. Results revealed that participants gained improvements in both aspects of balance and strength ($p<.05$); balance was improved by 18%, while the average improvement in strength was 21% among participants.

The National Disability Authority (NDA), in 2005, published a report on promoting the participation of people with disabilities in PA and sport across Ireland. There has been considerable recognition in Ireland in recent years that people with ID should be granted the same opportunities to access PA and sporting opportunities as the general population (NDA 2005). The report highlights a number of barriers which can prevent such inclusion in Ireland. These include, i) negative school experiences and poor physical education (PE) provision in schools, ii) lack of information and expertise in the area of ID, iii) poor community facilities and lack of access to facilities and programmes iv), ad hoc structures and approaches, v) lack of experience of the benefits of PA, vi) untrained staff and lack of accessible facilities, vii) lack of companions who can facilitate/assist people with disabilities to access facilities and programmes when required, and vii) a lack of a culture of general participation in physical exercise and sport in Ireland.

Special Olympics Ireland (SOI) was founded in 1978. It is a sports organisation set up for people with ID across the island of Ireland, and in many ways, is intended to address barriers which are highlighted in the NDA (2005) report. Over the past 37 years the organisation has grown significantly and today has approximately 9,000 athletes participating in 15 sports across 385 clubs throughout the island of Ireland. There were over 27,691 people registered on the NIDD at the end of December 2013. This figure shows that approximately 33% of people with ID are currently members of SOI. It remains the most popular source of PA for people with ID (McCarron et al. 2014). Research conducted by SO revealed that very little was known about the health status of people with ID. Using their unique global reach and access to the population of people with ID they launched the Healthy Athlete Programme in 1997. Healthy Athletes has provided more than 1,400,000 free health exams to athletes and trained more than 120,000 health care professionals worldwide. Exams include general fitness,

podiatry, hearing, vision, dental hygiene, healthy lifestyle choices, and sports physicals. Healthy Athletes has also evolved into a leading educator on the health of people with intellectual disabilities and an advocate for improved health care policies. The program's impact has been monumental, offering life-altering and life-saving opportunities for SO athletes and their families.

This study was carried out as part of a larger mixed method study "The SOPHIE project" (Special Olympics Programmes Health Impact Evaluation) which was funded by the Iris O' Brien foundation and was managed via Special Olympics Ireland. The larger study aimed to examine, over a near two year period, the health and wellbeing of individuals with ID who do and do not take part in SOI programmes. It looked to explore the impact and contribution of SOI to the health and wellbeing of persons with ID on the island of Ireland. Certain aspects of the study including ethical approval, recruitment, data collection co-ordination and development of study tools was done in conjunction with another MSc student who will be submitting a thesis on the dietary and nutritional intake of the study participants.

To date, no evidence exists on the impact of SOI participation on physical activity, fitness or BMI levels in Ireland. The current study looked to compare physical activity, physical fitness levels, BMI, and blood pressure (BP) of adults with an intellectual disability, who do and do not take part in SOI programmes. Despite the growing knowledge of evidence of the benefits of physical activity, no evidence exists on the benefits of participation in SOI programmes.

Justification for the current study

This study will provide detailed and comprehensive data on the PA levels, physical fitness and physical health of adults with ID aged 16-64 years in Ireland. Special Olympics Ireland is one of the most favourable sources of PA for people with ID; therefore a study evaluating the impact of SOI participation on PA, physical fitness and health is warranted.

Study Aim and Objectives

The aim of this study is to compare PA, physical fitness levels, BMI, and blood pressure of adults with ID, who do and do not take part in SOI programmes. The specific objectives are:

1. Describe the PA levels of people with ID using 7 day accelerometry and self-report questionnaire, and compare across participants who do and do not take part in SOI
2. Examine the physical fitness levels of people with ID using a modified Six Minute Walking Test, and compare across participants who do and do not take part in SOI
3. Create a health profile score using PA, fitness, BMI, and blood pressure data, and compare across participants who do and do not take part in SOI

Literature Review

The aim of this literature review is to explore whether regular involvement in physical activity (PA) is associated with beneficial outcomes in terms of health and wellbeing for adults with ID.

A number of questions have derived from this aim:

1. What are the health benefits of participation in PA for both persons with and without ID?
2. What are the current guidelines and compliance rates of PA for people with ID?
3. What barriers and facilitators do adults with ID experience in participating in PA and sports?
4. What is the best way to promote PA participation amongst the ID population?
5. What is the best way to assess PA level and estimate the health of adults with ID?

Sections to be included within this literature review include a definition and prevalence of ID, benefits of PA, PA guidelines, PA levels of people with ID and the general population, barriers and facilitators to PA amongst people with ID, and ways of promoting PA to people with ID will be explored. Methods for assessing PA participation, fitness levels and other health parameters of people with ID will also be included.

Intellectual Disability: definition and prevalence

Intellectual disability can occur without any other mental or physical condition. However often depending on the severity, ID often relates to other developmental disorders, damage in other organs than the nervous system only, additional disabilities and conditions such as sensory, speech and physical disabilities, autism, epilepsy, mental disorders, cerebral palsy and challenging behaviours. Together these can lead to limited capacity which results in boundaries to active daily living such as self-care, communication and community participation (Krahn, Hammond and Turner 2006).

In previous years the term Mental Retardation was used in the US. The term to replace mental retardation that has garnered the greatest international consensus is ID (Tassé, Luckasson and Nygren 2013). Throughout the literature, a variety of

words are still used, for example in Canada and the UK the terms learning disabilities and learning difficulties are commonly used (Gerber, Batalo and Achola 2012). In this study however, the term 'ID' is used to concur with the most frequently used international wording.

A meta-analysis carried out by Maulik et al. (2011) on 52 studies worldwide found that prevalence of ID occurred in approximately 1% of the population an estimation of 10.37/1000 (95% CI 9.55–11.18 per 1000 population). Estimations in the meta-analysis varied depending on income of country, age of the study population and study design. ID was more commonly found in low to middle income countries, often twice that of the higher income countries. This finding is similar to findings in the DSM-5 report carried out by the American Psychiatry Association (2013) where estimates of prevalence of ID also accounted for 1% of the American population.

In Ireland there were over 27,691 people registered on the NIDD at the end of December 2013. Based on 2011 census figures, this represents a prevalence rate of 6.04 people per 1,000 (0.6%) of the population (Kelly, Kelly and o'Donohoe 2013). Figures from the NIDD revealed that the life expectancy for those with ID is also increasing. In 1974, 28.5% of the ID population were over the age of 35years compared to 48.3% in 2012 (Kelly, Kelly and O'Donohoe 2013). It is suggested that the reason for the rise in life expectancy is improvements in neonatal care, nutrition and socioeconomic conditions (Cooper Melville and Morrison 2004). People with ID often have poorer physical and mental health than that of the general population. Often people with ID are less likely to be given proper

health screening and health promotion compared to others (Krahn, Hammond and Turner 2006). With a greater life expectancy within this population comes increased health needs and demand for services across Ireland for people with ID.

PA, health and wellbeing of adults with ID

Benefits of PA

People with ID are more likely to be overweight or obese and it has been widely reported in the literature that this population is less physically active than the general population (Hilgenkamp, van Wijck and Evenhuis 2012b; Frey, Stanish and Temple 2008). The three main causes of death in this population are respiratory disease, CVD and cancer (Prasher and Janicki 2002).

Defined by Caspersen, Powell and Christenson (1985), PA is as any force exerted by skeletal muscles that results in energy expenditure above resting levels. In daily life, PA can be categorized into occupational, sports, conditioning, household, or other activities of daily living (Caspersen, Powell and Christenson (1985). A report by the US Department of Health and Human Sciences (2008) identified that people with ID reap the same benefits when it comes to PA as the general population. Evidence indicates that PA and exercise can be beneficial to the human body in physical, psychological and social capacities.

Warburton, Crystal and Bredin (2006) suggest that regular participation in PA is important for primary and secondary prevention of an array of conditions such as several chronic diseases, including coronary heart disease, hypertension, Type 2 diabetes, osteoporosis, obesity, depression and colon cancer. It can also reduce the risk of premature death. This is particularly beneficial to those with ID who are at a greater risk of the co-morbidities previously mentioned (Prasher and Janicki 2002). Macera, Hootman and Sniezek (2003) found that inactive people are twice as likely to develop/die from chronic heart disease as active people. Participation in PA increases energy and strength which allows people to complete tasks independently whether at work or at home. Rippe et al. (1988) highlights even if a person was to perform activities of low- moderate intensity, like walking for pleasure, dancing or yard work on a daily basis, they would reap long term health benefits and reduce the risk of CVD.

Participation in PA can help to build and maintain strong bones, muscles and joint flexibility (Karinkanta et al. 2009). It reduces the risk of falls by improving balance and co-ordination (Warburton, Gledhill and Quinney 2001). Those with

ID have been known to suffer more fractions and breaks compared to people without ID. Van Schrojenstein Lantman-de Valk et al. (2000) found that people with ID were over three times as likely to suffer from fractures compared to the general population. Epilepsy occurs 15-30 times more often in people with ID than the general population, therefore the risk of falls and fractures greatly increases (Espie et al. 2003). Along with a balanced healthy diet, PA can help to control body weight and improve metabolism, decreasing the amount of circulating concentrates of insulin, reducing the risk of adult-onset diabetes. Overweight and obesity is a major problem within the ID population. Van Schrojenstein Lantman-de Valk et al. (2000) who examined a randomised computerised database generated by GP's in the Netherlands found that those with ID (n=318) were 3 times more obese than those without ID in the same study sample. Medications containing appetite stimulus, a lack of adequate PA and a lack of knowledge of health promotion activities such as healthy eating, all contribute to this ongoing problem.

Bartlo and Klein (2011) ran a systemic review of the literature to critically assess the effectiveness of PA interventions for adults with ID. Interventions studied include an array of PA methodologies such as walking, bicycle ergometers, resistance training, balance activities, dancing, weight bearing games, stretching and health education classes. Within this review they found compelling evidence to suggest that PA is extremely important in creating improvements in a number of aspects of a person's physical state including improvements in cardiovascular functioning, balance, muscular strength and overall quality of life. Rimmer et al. (2004) included adults with DS with mild to moderate ID (n=52) aged 38.6 ± 6.2, where improvements in cardiovascular fitness occurred in the intervention group. Participants increased cardiovascular function by 12% ($p<.01$). Podgorski et al. (2004) included balance and weight bearing exercises and found a staggering 70% average increase in strength within the study population of adults (n=12) with mild to profound ID aged 53.4years ($p=.0015$). Carmeli et al. (2005) conducted research with adults with mild ID (n=22). The PA intervention included balance and strength training. Clinical balance functional tests were measured by a modified Timed Get-up and Go test and Functional Reach test. Knee muscles strength were measured on a Biodex dynamometer. Participants

(60.9 ± 3.3 years) found a 20% improvement in balance and a 21% strength improvement. However, limitations of a small sample size do not allow for generalisation of the outcomes of the study.

The psychosocial benefits attributed to PA are just as significant as the physical benefits to the human body. The link between the benefits of PA to mental health has been a hot topic for many years. Andrews (2005) reveals that PA increases well-being by increasing pride in physical accomplishments, improving body image and promoting more self-confidence. Strohle (2009) conducted a systematic review on the literature surrounding PA, anxiety and depressive symptoms. Findings revealed that besides small uncontrolled studies, recent well controlled studies suggest that exercise training may be clinically effective, at least in major depression and panic disorders. Bradley (1996) identified how this occurs, indicating it is caused by an increased blood flow to the brain during PA, which triggers the release of critical neurotransmitters associated with better mood and improved mental alertness. These neurotransmitters include serotonin, epinephrine, norepinephrine and dopamine. PA has also been shown to have a mitigating effect on challenging behaviours in people with ID (Washburn et al. 2002; Nishiyama, Kuwahara and Matsuda 1986; Moone and Renzaglia 1982).

Weiss et al. (2003) examined the benefits of being involved in SO in relation to self-concept of perceived physical competence, social acceptance, and general self-worth. They also explored actual physical competency of participants. Ninety-seven individuals with ID were randomly selected. Self-concept and behaviours were measured both by direct interview and by parental report. Results highlighted that the number of competitions experienced, the number of medals and ribbons obtained, the number of years involved in SO, and the number of sports experienced have all been found to be positively correlated with different facets of an athlete's self-concept.

Often people with ID can experience difficulties in developing positive self-concepts of both physical and social competencies. These negative thoughts may have derived from social isolation situations, discrimination and stigmatization. Participation in PA allows for the prevention of isolation (Mutrie et al. 2007); group activity has been proven to increase levels of participation in PA due to the

enjoyment and social support it provides (Allender, Cowburn and Foster 2006). Physical activity provides an outlet for people to share their experiences, difficulties and achievements (Allender, Cowburn and Foster 2006). Darrah et al. (1999) carried out a community based programme for adolescents with cerebral palsy (n=23) consisting of aerobics, strength training and stretching for a period of 10 weeks. Significant changes were found in muscle strength (using a hand held dynamometer) and perceptions of physical appearance of study participants (using the SPPA) ($p \leq 0.01$). Although results of the intervention revealed that the study participants did not think their competency for tasks changed, they did however feel better about their physical appearance in general. Parents commented that there was a noticeable difference in their children's interactions in social encounters.

Blinde and McClung (1997) wanted to explore the impact of participation in recreational PA programmes on the physical and social selves of individuals with physical disabilities. The study was carried out in Illinois on 11 women and 12 men. Individuals completed personalised programmes including horse riding, swimming, weight lifting, bowling, tennis, fishing, walking and tai chi. Tape recorded interviews were carried out post programme and analysis revealed that the activities were responsible for impacting not only on the physical self, including experiencing the body in new ways and redefining physical capabilities, but also on the social self in the areas of 1) expanding the social interactions and experiences and 2) initiating social activities in other contexts. The gains discussed within this study suggest that individuals felt a greater control over their physical and social lives as a result of participation in PA. Both studies carried out by Darrah et al. (1999) and Blinde and McClung (1997) include individuals with different forms of physical disabilities. It is important to note that people in the current study not only presented with ID but also with an array of physical disabilities. Therefore to highlight the potential benefits gained from PA for both populations is extremely important.

PA guidelines

Due to the significant benefits attributable to PA, recommendations for the amount of PA people should accumulate in order to garner health benefits are

widely available in the hope of improving public health (World Health Organization and UNAIDS 2007). The U.S Department of Health and Human Sciences (2008), the American College of Sports Medicine (ACSM), the American Heart Association (AHA) have all effectively supported each other's views with regard to the PA guidelines and recommendations set out for the global strategy for better health which will be outlined below (American College of Sports Medicine 2011).

These guidelines include recommendations for all members of the population including people with disabilities. Young people (aged 2-18) should accumulate at least 60 minutes of MVPA every day. They should also put emphasis on muscle strengthening, flexibility and bone strengthening activities at least 3 times per week. All adults (aged 18-65) should accumulate at least 30-60 minutes of moderate-intensity aerobic activity 5 days per week or engage in 20- 60 minutes of vigorous activity 3 days per week. Activity must be at least 10 minutes in duration to count towards daily goals and that a combination of moderate and vigorous-intensity PA is acceptable. Strength training at least twice weekly is recommended. Programs should consist of 8-10 exercises for at least 1 set of 8-12 repetitions each. With regard to older adults (aged 65+) the guidelines are similar to that of adults with 30 minutes 5 days a week or 150 minutes over 7 days being recommended. The older adult's recommendations for aerobic exercise define moderate and vigorous activity based on perceived exertion in addition to metabolic equivalent of tasks. They are also encouraged to strength train a minimum of twice weekly. The older adult's strength program should include 8-10 exercises using 10-15 repetitions per exercise. Older adults are also encouraged to maintain flexibility by stretching or other activity at least 10 minutes twice weekly. They should also include some balance training, especially for those at risk for falls (Haskell et al. 2008).

With regard to the EU, guidelines were based on the WHO guidelines which were far less prescriptive as the American guidelines (Oja et al. 2010). Guidelines focused on targeting policy actions in order to promote and increase PA. Both the American and European guidelines were in agreement that some activity is better than no activity and the new up guidelines highlighted the need for inclusion of

vigorous PA and activities for muscle strength and bone health in conjunction with 30minutes of PA at moderate intensities (Oja et al. 2010).

The National Guidelines for PA in Ireland (Department of Health and Children, Health Service Executive 2009) are again consistent with recommendations worldwide, and include recommendations specific to people with a disability concurrent with the guidelines set out for America in 2008. Where possible, people with ID should aim to meet the guidelines set for adults at 30 minutes moderate intensity on 5 days a week. When adults with disabilities cannot meet these guidelines, they should aim to be as active as their ability allows taking into account specific health risks and limitations and should avoid inactivity where possible.

When the National Guidelines for PA in Ireland were drawn up by the Department of Health and Children and the Health Service Executive (2009) they reflected the international expertise and evidence which supports PA for a healthier life. While achieving these recommendations will improve cardio respiratory function, in order to see an expansion of benefits such as weight maintenance, exercise exceeding these recommendations is encouraged (American College of Sports Medicine 2011). Similarly, Haskell et al. (2008) suggests that to increase the likelihood of better health and wellness, people should aim to be active or accumulate some activity on more or all days of the week.

PA levels; general population and people with ID

Although the importance of PA is continually being supported and highlighted by research and considering worldwide recommendations have been created to garner health benefits, there are still low levels of PA evident in the general population and in special populations such as people with ID, these will be highlighted in the following section.

In 2007, an updated National Survey of Lifestyles Attitudes and Nutrition (SLÁN-07) showed that 41% of the general adult population of Ireland took part in MVPA for at least 20 minutes three or more times a week. There have not been many advances in these levels of activity over the past ten years comparing with

previous SLÁN figures of 40% in 2002, and 38% in 1998. Thirty-five percent of people with disability reported no PA of at least moderate intensity compared to only 10% of the sample with no disability by Hannon, Fitzsimon and Kelleher (2006). This problem is not exclusive to Ireland, as research has shown worldwide that people with ID are living more sedentary lives than their counterparts (Messent, Cooke and Long 1999; Philips and Holland 2011).

A study carried out in England by Philips and Holland (2011) examined PA levels of people with ID with and without DS. The sample consisted of people between the ages of 12-70 years with mild to severe ID. PA was assessed using the Actigraph GT1M accelerometer for 7 days. Regardless of age or gender, most of the waking day was spent in sedentary behaviour (605.3 mins ± 95.3 for males; 616.0 mins ± 70.6 for females). MVPA minutes per day included 40.4 ± 24.1 for males and 30.2 ± 13.7 for females. Very little time was spent in vigorous activity. MVPA was very sporadic with very few people accumulating sustained bouts. Of the 152 participants, none met the UK recommended minimum guidelines for participation in PA. These findings are concurrent with research carried out by Messent, Cooke and Long (1999) who created a 10 week exercise programme carried out by all participants who were adults with ID (n=24). Post 10 week interviews followed. Interview questions included activities carried out in the last week, activities enjoyed/disliked and why, opinions on the 10 week programme and thoughts on the fitness test carried out pre programme. Results found that adults with ID (n=24) were significantly more likely to lead sedentary lives than those of the general population within the UK.

Similarly, a process of health screening for people with ID began in Birmingham in 1995 to facilitate equal access to health services (Wells et al. 1997). One hundred and twenty people with ID accepted a health check. This included an assessment of diet, smoking habits and alcohol consumption, relevant family history, PA levels, blood pressure (BP), body mass index (BMI), urinalysis, and blood tests (including thyroid function and cholesterol). In order to quantify the levels of PA, a questionnaire was given to 110 participants and 46 people from the general population. The results showed that a staggering 49% of the sample did not participate in any form of moderate intensity PA during the last four

weeks. Compared to the control group where 43 (95.5%) out of the 46 recruited from the general population did some form of MVPA over the last four weeks (Wells et al. 1997).

Tucker, Welk and Beyler (2011) estimated the level of compliance to PA recommendations set out for Americans in 2008. Using data from the National Health and Nutrition Examination Survey (NHANES) 2005-2006 estimations of PA levels were found using self-reports and objective measures of accelerometry. According to NHANES accelerometer data 2005–2006, fewer than 10% of U.S. adults met the PA guideline. Although this seems like a very low level of compliance, Dixon-Ibarra, Lee and Dugala (2013) conducted a comparative study on older adults in America with ID compared with younger adults with ID and older adults without ID. Pedometers and accelerometers were used to determine PA levels of the study participants (n=109). Results showed that all participants in the study spent 60-65% of their time in sedentary behaviour and older adults with ID performed less activity than both of the comparative groups. Only 6% of the older adults with ID met the national guidelines of 150 minutes of MVPA or 75 minutes of vigorous activity of bouts greater than ten minutes across the week (U.S Department of Health and Human Sciences 2008). This study highlights that individuals with ID's level of compliance of PA is even lower than the general population figures.

Temple, Anderson and Walkley (2000) used accelerometry to examine the PA patterns of 6 adults with ID in Australia living in a group home. On average per day, participants spent 10 hours lying down, 6 hours sitting, 3 hours standing, 3 hours undertaking personal tasks, and engaged in light to moderate sport, leisure or work at other times. Only two participants met the Australian guidelines for 30 minutes MVPA per day and another met the guidelines when he was well. MVPA was accrued mainly by walking for transport and gardening as part of supported employment. A follow up by Temple and Walkley (2003) measured PA levels of 37 adults with ID. Proxy 3-day activity was recorded by care staff and Caltrac accelerometers were also worn by participants for 3 days (2 week days and 1 weekend day). Results showed that of the 37 recruited for the study; only 32% met the national guidelines for PA of at least 30 minutes per day of MVPA. The majority of participant's time was spent being sedentary with a proportion of

people (14%) spending one hour a day in light manual work. In comparison with the general population in Australia, Miller and Brown (2004) looked to examine compliance with PA guidelines of working Australian adults. One hundred and eighty-five adults wore a pedometer and recorded the number of steps taken each day for 7 days. On the 8th day, they completed a self-report survey that asked about frequency and duration of different activities during the previous week. Just over half the men (53%) and 45% of the women met the current national PA guidelines.

Peterson, Jans and Lowe (2008) monitored steps taken by adults with mild to moderate ID living in community based support using pedometers (n=131). Consistent with previous ID research (Frey, Buchanan and Sandt 2005) all participants wearing a pedometer for ≥10 h on ≥5 days, including a weekend day, were included in the data set. Results found that only 20 participants (15.3%) achieved the public health guideline of 10,000 steps per day. Limitations of this study need to be addressed as those participating were volunteers and mostly serving as their own guardians meaning this may be favouring a more active and able bodied population.

The results from the studies mentioned above highlight that low levels of PA engagement are a worldwide problem which needs to be addressed. Assessing and recognising the barriers for participation of PA for this population is potentially the first step in correcting this growing worldwide problem.

Barriers to participation in PA for people with ID

In order to overcome the low levels of PA engagement in the general population and in particular for the study population of people with ID, it is important to highlight the reasons why people are not engaging in PA as they should, to create better health outcomes. A literature review carried out by Dowling et al. (2012) identified three clear categories with regard to barriers to participation in PA within the ID population; namely environmental (financial constraints, transport, weather, time, lack of equipment) , structural (inadequate support from staff/families) and personal barriers (disinterest, feeling incompetent, personal concerns of safety). These three categories are of similar content to those

highlighted in the recent study by Brooker et al. (2015) who sought to examine the views of people with ID in Australia on the barriers to inform a walking and social support program. Adults with ID have almost no control over their environment and few opportunities to be physically active (Messent, Cooke and Long 1999). Often people with ID do not have access to sporting activities/ facilities and equipment (Howie et al. 2012; Biddle and Mutrie 2007). Howie et al. (2012) conducted a survey of 103 adults with ID in the USA to investigate the availability of PA resources in their environment. The survey revealed that for the people with ID living in a group setting, equipment was more accessible (55.4% had sports equipment) whereas for those who were living alone or with families, often PA equipment was not available (39.8% had sports equipment).

Financial constraints are a common theme running through many papers with regard to barriers to participation in PA for people with ID (Mahy et al. 2010; Robertson and Emerson 2010; Bodde and Seo 2009; Temple 2007; Hawkins and Look 2006; Heller, Hsieh and Rimmer 2003; Messent, Cooke and Long 1999; Frey, Stanish and Temple 2008; Barr and Shields 2011). Often, activities require high costs and with a large number of the population of ID being on the lower end of the economic ladder this is a major concern (Emerson et al. 2008; Robertson and Emerson 2010). Howie (2012) conducted a large scale survey of 2,784 people with ID in England. Findings suggest persons with ID living in poverty and in deprived areas were less likely to be involved in PA. It was also revealed that those living in the aforementioned areas were more likely to report a desire to take part in sports activities.

Similar to the general population, accessing transportation is another environmental concern in relation to PA participation for people with ID (Heller, Hsieh and Rimmer 2003; Temple 2007). Often, people with ID cannot access transport independently and so relying on others can cause increased difficulties (Messent, Cooke and Long 1999). Similarly, findings by Frey, Buchanan and Sandt (2005) concur that transportation was a primary factor in the ability to access activity opportunities. Weather has also been found to be a contributing factor with regard to participation in PA in people with ID (Bodde and Seo 2009, Temple 2007 and Frey, Buchanan and Sandt (2005). A study carried out in

Canada by Temple (2007) looked to examine the relationships between participation in PA/sedentary behaviour and factors consistent with behavioural choice theory (Einhorn and Hogarth 1981): enjoyment, preference and barriers in people with ID (n=37). They looked at the correlation between lifestyle and barriers and results showed that only those participants who were classed as 'sedentary' reported that bad weather was a barrier. However, those who fell under the 'active' category did not view the weather as a determining factor.

From a support perspective, service user to staff ratios can often be a constraint to participation in PA (Messent, Cooke and Long 1999). Often, staff cannot provide assistance in ensuring safe and adequate PA for individual needs (Temple 2007). Care providers and supervisors voice that there is a lack of clear policies in residential and day service providers which also contribute to difficulties in implementation of PA (Messent, Cooke and Long 1999). Some staff do not feel obliged to promote PA within the workplace as they do not see it as part of their job so often do not prioritise PA over other activities (Temple 2007; Messent, Cooke and Long 1999). Heller, Hsieh and Rimmer 2003 discovered that staff who were aware of the benefits of PA were more likely to promote PA to the service users whereas those who were not aware/not interested were less likely to do same. Unless the people surrounding them are in the position to participate in PA or at the very least promote it, then there is a lesser chance for individuals with ID to have the opportunity to get involved (Howie et al. 2012).

On a personal level, people with ID often lack the internal motivation needed to kick-start PA, they may also have concerns in relation to their health and body image which can inhibit participation in PA (Temple & Walkley 2000). Similarly, they may feel incompetent in completing new tasks when there is no one to guide and teach them how to do things right (Temple & Walkley 2007; Heller, Hsieh and Rimmer 2003). Messent, Cooke and Long (1999) who carried out interviews with 24 adults with mild to moderate ID reported that people with ID expressed frustration in needing to rely on others and not being able to take part in PA freely and independently. The study highlighted that the current lack of resources and responsibilities associated with community care deny many people with learning disabilities the choice to live a physically active healthy lifestyle.

Facilitators for PA

Within the recently conducted literature review by Dowling et al. (2012), four main factors have emerged in the context facilitating participation in PA in people with ID. The four factors include leadership, competence, motivation and the social aspect.

Leadership is extremely important for people with ID; this includes support from people surrounding them by helping to initiate participation in PA or indeed providing support during training or competitions (Peterson, Janz and Lowe 2008). Barr & Shields (2011) conducted interviews with 20 parents with children with DS, aged between 2 and 17 years, to investigate what factors facilitate PA and what factors are barriers to activity for their children. What emerged was that parents felt that they had a positive role in the participation of activity of their children. Children were more likely to be involved in activities when their parents enjoyed the activity, were aware of its benefits and were actively involved. It was found that proactive parents were more likely to go and find resources for their children to be involved in activities and sport.

In order for people with ID to feel competent and confident in what they are doing it is important for them to have a strong network surrounding them. The social aspect is also an extremely important component in relation to PA participation and people with ID (Dowling et al. 2012). Having a strong network and guidance allows the individual to become familiar with the activities and skills that need to be developed (Heller, Hsieh and Rimmer 2003). Peterson, Jans and Lowe (2008) were one of the first to provide empirical evidence for evaluating the link between self-efficacy and leisure time PA in adults with ID. A self-report checklist was used to measure frequency of participation in physical activities. In both younger and older adults with ID (n = 159), self-efficacy was significantly associated with PA behaviour (younger adults, r = 0.37; older adults, r = 0.32). Results further showed that the more social support individuals with ID had, the more self-efficient they felt about tasks related to PA, and therefore those that reported to have higher levels of self-efficacy also reported higher levels of leisure time PA. This study highlights the importance of interventions which aim

to increase self-efficacy of individuals with ID and in return may positively have an impact on increasing participation in PA for this group.

Meeting new people and engaging in activities with likeminded and similarly capable people allows for individuals to feel acceptance and allows them a sense of belonging (Trost et al. 2002). Similar to the general population, motivation for initial participation and fostering ongoing activity is linked to friendships and social connections attained when participating in activity (Trost et al. 2002). PA can also offer an avenue for people with and without ID to become acquainted (Castagno 2001). Developing peer relationships was reported by Castagno (2001) who looked at outcomes of a unified sports programme. They found that people were willing to make friends which led to a greater willingness to stay within the programme. It allows for times of fun and engagement with family members in a scene that is otherwise not usually catered. Temple (2007) highlighted the importance of the social aspect within PA where 43% of sedentary individuals (i.e. less than 5000 steps per day) with ID reported no one to participate with as a barrier to PA whereas only 15% of active individuals (more than or equal to 10, 000 steps per day) reported the same barrier.

Temple (2009) looked to examine the factors associated with high levels of PA among adults with ID in Australia. They conducted in- depth interviews with 13 ID participants who were classed as physically active after they accumulated more than or equal to 10,000 steps per day while wearing pedometers for one week. Themes emerged from the interviews which may help to promote PA in people with ID. Participants voiced that being shown how to do things was extremely important. Good role models including family members/care staff willing to walk for transport and who regularly participated in exercise and activity with the individuals with ID was a positive factor for increased participation. Being able to provide transportation, access to affordable activities, fostering social aspects and keeping costs low were also highlighted as important factors in promoting and sustaining in PA.

PA promotion for people with ID

According to the NDA (2005) report, there is a need to ensure that equal opportunities exist between people with disabilities and their peers without disability with regard to access to quality PA and sport. The Irish National Children's Council (2001) states that all children should have access to play, sport and recreation and cultural activities. All children with disabilities are entitled to the services needed to reach their full potential.

Ireland has much to learn from organisations for disability sports in other countries such as the Federation of Disability Sport Wales (FDSW) in Wales, the English Federation of Disability Sport (EFDS) in England and the Australian Sports Commissions Disability Sports Unit (DSU). The development of more organised approaches to sport and PA equity has led to improvements, in terms of participation, quality experiences and achievement. Although countries have their own approaches, leadership and co-ordination at a national level has been paramount.

There are many initiatives being run across Ireland to promote participation in PA among those with disabilities. CARA, Adapted Physical Activity Centre is an IT Tralee initiative, aimed to co-ordinate, facilitate and advocate for inclusion of people with disabilities in sport, PA and physical education in Ireland (CARA 2015). IT Tralee have also launched a UNESCO Chair which looks to transform the lives of people with disabilities through inclusion in PE, sport, fitness and recreation by education, advocacy and collaborations between higher education institutions, service providers, users and industry (UNESCO 2015). Cerebral Palsy Sport Ireland (CPSI) is the official national governing body for people with cerebral palsy in Ireland. The Persons with Disability in Ireland (PWDI) is an organisation which brings people together both locally and nationally to work on issues affecting people with disabilities. It caters for all people with disabilities including those with physical, emotional intellectual or mental disabilities. It is the only national cross disability organisation funded by the Government. The NDA is the independent state body providing expert advice on disability policy and practice to the Irish government. Special Olympics Ireland provides year-round sports training and athletic competition in a variety of Olympic-type sports

for children and adults with ID. It is a popular organisation which provides opportunities for involvement in sport and enhances social networks. To date SOI is the most popular source of PA for people with ID (McCarron et al. 2014).

Assessing PA participation

There are numerous methods in which to measure PA levels and patterns of people with ID. The following section will go on to discuss some of the most often used techniques for collecting data on PA participation for people with ID. Direct measures of PA included in the section are the use of direct observation, pedometers and accelerometers. Indirect measures included in the section are questionnaires or interviews with people with ID or administered to families/friends that live or work with them. Factoring in logistics and feasibility these were the methods considered For the purpose of this study.

Direct Measures

Direct observation

Direct observation is often called 'non-intrusive' as the subjects go about as normal without being disturbed by the observers. Often, the observer sits passively while documenting events and recording the behaviour of the subject (Temple, Anderson and Walkley 2000). However, observers need also to be aware of the 'Hawthorn Effect' meaning that people may perform better than their normal standard because attention is being put on them (Sirard et al. 2005). This type of method can be troublesome and time consuming for large scale geographical studies but is advantageous on small scale epidemiological research (Bailey et al. 1995). In particular with PA, direct observation can capture the social and physical context of activity, while also allowing the observer to identify the duration, intensity and frequency of an activity (Bailey et al. 1995).

Direct observation was used by Temple, Anderson and Walkley (2000) with a population of 6 adults with ID living in a group home. Participants were observed for seven consecutive days. Trained observers recorded activity every minute. A Physical Activity Record was then used to measure PA. However, data on energy expenditure was also calculated using accelerometers so that critical appraisal of the accuracy of the direct observation records could be carried out.

Pedometers

Pedometers are small relatively inexpensive devices worn at the waistband ensuring that they are facing up and down without tilting. They are worn from waking until bedtime, except during bathing or swimming (Bravata et al. 2007). They record the number of steps by detecting the motion from the hips and provide an estimate for the distance walked (distance= number of steps x step length). Previously, they were worn by fitness enthusiasts but pedometers have become more popular with the general public for everyday measure and motivation and have also become popular for research purposes (Bravata et al. 2007). Pedometers are useful when conducting research with adults with ID as they provide a direct and objective measure of PA and do not rely on participant or proxy recall (Beets and Pitetti 2011). However, a downfall of pedometers is that they cannot give us an estimate as to the duration of time spent doing or type of intensity of PA (Beets and Pitetti 2011).

The UK Department of Health and the US Surgeon General set recommendations of 10,000 steps per day for the general population (Tudor-Locke and Bassett Jr 2004). Research indicates that walking is the most popular activity within the ID population (Draheim, Williams and McCubbin 2002). Regardless of instrumentation choice, the utility of any step output is limited without the ability to translate public health guidelines in terms of steps/day (Tudor-Locke et al. 2011). Tudor-Locke and Bassett Jr (2004) set indices for steps in healthy adults to determine PA levels. Fewer than 5,000 steps is sedentary; 5000 to 7499 steps is low active; 7,500 to 9,999 steps is somewhat active; more than 10,000 is active; and more than 12,500 is highly active. Tudor-Locke et al (2011) conducted a review paper to translate public health guidelines in terms of steps/day for older people and special populations. In this paper it indicated that special population's averaged 1,200-8,800 steps/day. However 10,000 may be an unrealistic goal for people with ID. Those living with a disability tend to do a lower level of background activity therefore this affects estimation of PA per day. Steps accumulated should be taken over and above activities performed in the course of daily living, be of at least moderate intensity accumulated in minimally 10 minute

bouts, and add up to at least 150 minutes over the week to comply with the public heath recommendations set out for adults (Tudor-Locke et al. 2011).

Pitetti, Beets and Flaming (2009) looked to examine the accuracy of pedometer steps and time for youth with intellectual disabilities during dynamic movements. Twenty-four youth's with ID (13 girls, 13.1 ± 3.2 yrs; 11 boys, 14.7 ± 2.7 yrs) were videotaped during adapted PE class while wearing a Walk4Life 2505 pedometer in five locations around the waist. Researchers viewed each videotape and recorded observed steps and activity time. Observed findings were compared with pedometer recorded steps and time. On average, pedometer registered steps were underestimated by approximately 14% ± 16.5%, whereas pedometer registered time was overestimated by approximately 8.7% ± 21.8%. The findings indicate that the accuracy of pedometers may be compromised during dynamic movement for youth with ID.

A follow on study by Beets and Pitetti (2011) examined the use of pedometers to measure MVPA for youth's with ID. Participants were 38 children and adolescents (11.8 ± 1.8 years) who were asked to walk on a treadmill at 2kmph and the speed was increased by 0.5 every 2 minutes. Steps were counted by trained observers using hand-tally counters. Participants also wore heart rate monitors. From there the observers were able to work out heart rate reserve from individual's resting heart rate obtained prior to the test. Data were collected during the final minute of each speed. Heart rate at each speed was transformed into percentage of heart rate reserve. Percentage of Heart Rate Reserve (HRR) corresponding to 40% HRR or higher was used to define MVPA. On average, the study participants completed 122 steps per minute. Beets and Pitetti (2011) suggest that these findings can now be used by health professionals as thresholds to promote and evaluate MVPA within this population.

Accelerometers

An accelerometer is a small, lightweight device which measures the body's acceleration. It is generally worn on the hip but some monitors can also be worn on the wrist or ankle (Lee and Shiroma 2014). Accelerometers are sensitive in that they can detect the difference between human movement and movement

outside of the human range (e.g speed bumps in the car). The device operates by measuring acceleration across a given axis (Mathie et al. 2004). Multiple axis measurements can be stored in a single monitor allowing for movement through different planes to be identified. The sensor converts movement into electrical signals (counts). These counts are summed over a specified period of time (epoch) and stored. The counts can then be compared to laboratory established cut points to relate to MET values (Mathie et al. 2004). The general industry standard age range for classifying someone as adult or child are as follows; infant = less than 1 year old, toddler = 1 to 2 years old, pre-School = 3 to 5 years old, children = 6 to 18 years old, adult = 19 and older. There are many cut points that can be used to quantify activity levels depending on the population under examination (Freedson, Melanson and Sirard 1998, Troiano et al. 2008).

Accelerometers are becoming more feasible in research as they involve minimal inconvenience to the participant and reasonable cost to the investigator (Esliger and Tremblay 2007). Accelerometers are superior to pedometers as they can identify the intensity and duration as well as frequency of PA performed (Mathie et al. 2004). These devices can be used to quantify total daily activity and their sensitivity can also detect light intensity activity and sedentary behaviour, however the accelerometer cannot detect upper body movement or the type of activity performed so may underestimate activity (Lee and Shiroma 2014). Accelerometers are not waterproof so cannot be worn when swimming and are delicate so cannot be used when doing contact sports. The device is however useful for special populations because as already mentioned, walking is the preferred activity for people with disabilities.

Frey, Buchanan and Sandt (2005) looked to compare PA levels of adults with ID (n=22), sedentary controls (SC) (17) and active controls. (AC) (n=9) in the USA. Subjects wore a portable accelerometer (Manufacturing Technology Inc [MTI] Model 7164, Shalimar, FL) during waking hours, except bathing or water activities, throughout a 7 day assessment period (5 weekdays, 2 weekend days). Accelerometers were programmed to collect data in 1-min epochs during the assessment period. Activity counts were categorised using the equation by Freedson, Melanson and Sirard (1988). Bouts of continuous moderate, hard, and very hard PA were defined as consecutive time >1952 counts/min. Time frames

used were 5 to 10 min, 10 to 20 min, and 20 to 30 min. For example, a 10-min continuous bout of moderate PA required that all 10 min be > 1952 counts/min. The proportion of each group achieving 30-minutes of MVPA per day was: ID, 28%; SC, 47%; and AC, 89%. The group with ID did not regularly engage in continuous MVPA greater than 10 minutes in duration. The main sources of PA for those with ID and SC groups were housework, yard work, walking and, for the former, SO. Active control participants engaged in a variety of sports/activities such as jogging and tennis. It was concluded that adults with ID are similar to the general population that is classified as sedentary.

Indirect Measures of PA

Self-Report Questionnaires/interviews

Research which includes perspectives of individuals with ID remains limited, which can be attributed, at least in part, to continuing debates about the most effective means of including people with ID in the research process and ensuring the credibility of researchers' interpretations of the information provided by these individuals (Mactavish, Mahon and Lutfiyya 2000). In the past, research tended to be on people with disabilities rather than with people with disabilities. It is now becoming more accepted that people with ID should be the best authority of their own life and that they should be able to express their views and opinions. People with ID have over the past twenty years or so, become increasingly seen as reliable informants who hold valid opinions and have a right to express them (Stalker 1998).

In many cases, the use of questionnaires developed for the general population is inappropriate for people with ID because of the respondents' inability to comprehend the question and express an answer clearly and because the psychometric properties may not be applicable to this population. There are two main tools used in collecting data for people with ID including self-reports and proxy report. Self-report questionnaires are where the researcher gains information directly from an individual. Due to limitations among some people with ID on understanding and recalling information and articulating responses it can often be an unrealistic objective within research to include self-reporting

(Fujiura 2012). Finlay and Lyons (2001) examined methodological issues of self-reporting and interviews for people with ID. They suggest that this population "may be too heterogeneous in terms of personal history and linguistic and cognitive abilities for any single questionnaire to be valid for the whole population" (p. 329). Issues with self-reporting also include the use of types of questions. Questions on judgements of time and frequency are problematic for the ID population concurrent with the general population. Rating scales can often be unsuitable and questions with yes/no answers tend to yield better results for those with ID. People with ID have a tendency to say yes to a question regardless of the content or similarly they might select the last option given to them regardless of their true opinions (Emerson, Felce and Stancliffe 2013).

When it is not feasible to conduct research through self-reporting, a process of proxy reporting can be adopted. This is a process where an individual deemed equipped to provide adequate information on behalf of a person is used (Emerson, Felce and Stancliffe 2013). The proxy does not provide their own perspectives more so they either give a detailed account of the situation or behaviour of the individual or they answer questions in a way that they believe person they are representing would respond. Proxy reporting allows for the individual to report on a behaviour or give details of the person's life however, how confident can we be in that someone could relay the thoughts and feelings of a person with ID when the person themselves often cannot express these ideas for themselves (Perry and Felce 2002). There is currently no gold standard questionnaire to assess the health status of people with ID in Ireland or indeed worldwide. Considerations should be made when conducting direct interviews or questionnaires with people with ID. This is to ensure that the person understands what is being asked of them so as to extract maximum information from the data collection tool used.

I have discussed a number of the most used methods of assessing PA in this population but based on an in depth examination of all of the possible choices, and the feasibility of use of each I have chosen to use accelerometry and a self-report questionnaire with the use of visual aids and with family member support if required for the self-report questionnaire, as my methods of gathering data on PA participation of the participants in the current study.

Measuring PA and other health parameters in people with ID

Certain measures can be taken to help indicate the physical health of a population, including fitness, body composition and BP.

Cardiovascular fitness

Cardiovascular fitness can be described as the cardiovascular systems ability to supply skeletal muscles with adequate oxygen during sustained PA (U.S. Department of Health and Human Services, 2008). A poor standard of cardiovascular fitness is a risk factor for cardiovascular disease (CVD) and all-cause mortality, musculoskeletal health conditions, such as osteoporosis and loss of muscle mass, and increases the risk of falls (World Health Organization and UNAIDS 2007). Existing empirical data have established that individuals with ID as a group have a lower level of fitness than the general population, further heightening the risk factors to this population (Pitetti, Beets and Flaming 2009, Fernhall, Tymeson and Webster 1988). Low physical fitness can be reversed and prevented by adapting a healthier lifestyle and increasing levels of PA and/or structured exercise (World Health Organization and UNAIDS 2007).

A longitudinal study conducted in the USA by Graham & Reid (2000) looked to describe the change in physical fitness of middle-aged adults with ID over a period of 13 years (n=32). Using the Canadian Standardised Test of Fitness participants were evaluated for cardiovascular endurance, muscular strength, muscular endurance, flexibility, and body composition. Results indicated a significant decrease in fitness in all areas except flexibility, muscular strength, and the muscular endurance test of push-ups. Similar to the general population, there is decline in fitness levels over time. However as the people with ID were already presenting low levels of fitness to begin with, after the 13 year period, the levels they were performing at placed them at a higher risk of developing diseases and losing independence.

Similarly, Hilgenkamp, van Wijck and Evenhuis (2012b) investigated low physical fitness levels of older adults with ID in the Netherlands (n=1050). Comfortable walking speed, muscle strength (grip strength, muscle endurance (30sec chair stand) and cardiorespiratory endurance (10 m incremental shuttle

walking test) were tested. Results from all tests conducted were compared with reference values from the general population (Bohannon et al. 2007; Bohannon and Andrews 2011) Across all age ranges, approximately two-thirds of the entire study population scored according to the authors a "below average" or "impaired" score meaning their scores were less than the lower limits of the 95% confidence interval of a specific stratum (Bohannon et al. 2007). Even the youngest age groups in this study (50-59 years) achieved similar or worse results than age groups 20–30 years older in the general population. The authors conclude that low physical fitness levels in older adults with ID demonstrate that this group is prone to unnecessary premature loss of functioning and health problems and maintaining physical fitness should have priority in practice and policy (Hilgenkamp, van Wijck and Evenhuis 2013).

Assessing cardiovascular fitness

Maximal oxygen uptake (VO^2 max test)

The VO^2 max test is widely accepted as the single best measure of cardiovascular fitness and maximal aerobic power. Accurately measuring VO^2 max involves a physical effort sufficient in duration and intensity to fully tax the aerobic energy system (American College of Sports Medicine 2013). The highest achieved oxygen uptake during a maximal cardiorespiratory exercise test can be considered as VO^2 max when a plateau in oxygen uptake with an increase in work rate is reached. Often, a plateau is not reached, in this case there are secondary criteria to check whether VO^2 max is reached (a) a plateau in HR with an increase in work rate or within 10 beats of the estimated maximal HR (HRmax), (b) respiratory exchange ratio (RER) > 1.0, and (c) high levels of lactic acid in the minutes following exercise (McArdle, Katch and Katch 2006). When these criteria are not met, the highest achieved oxygen uptake during the test is called VO^2 peak. VO^2 max tests are carried out in laboratory controlled settings with very sophisticated equipment including a treadmill or bicycle ergometer with open circuit spirometry using standardised protocols (American College of Sports Medicine 2013). However if access to equipment/personnel is limited then sub maximal testing can be performed. In the case of individuals with ID, test results are often called VO^2 peak, which means that they have reached volitional exhaustion, the

point at which the participant feels he/she can no longer continue (Climstein et al. 1993).

In order to carry out a reliable and valid assessment of cardiorespiratory fitness when working with the ID population, certain considerations need to be addressed. Often, assessing cardiorespiratory fitness of people with ID can be difficult. Performance can be negatively affected due to variations in testing methodology, adherence, co-ordination, inability to self-pace, new environment and new actions, learning and motivational issues (Rintala et al. 1992). Often a lack of internal motivation can affect performance during fitness testing with participants not understanding why they need to walk faster (Waninge et al. 2011). Individuals need to be able to understand and comprehend the tasks at hand so that they can perform to their full potential. To overcome this, familiarisation of testing should be carried out where possible for either maximal or submaximal testing (Rintala et al. 1992).

Although a number of fitness test batteries have been developed in past years, many have not been validated for the ID population. Tests that have been used with this population include the VO^2 max test, the Six Minute Walk test (6MWT), Rockport fitness walk test (RFWT) and the Multi-stage fitness test. A description of these tests, along with information on the reliability and validity in each case, are presented below.

Climstein et al. (1993) examined the validity of using the predicted VO^2 max equations drawn up by the ACSM where gender, age and level of PA are included. The study participants were young adults with DS (n = 15) and young adults non-DS (n = 17). Individualised maximal treadmill protocol was used to predict peak HR and peak oxygen consumption (VO^2 max). Subjects walked at 4.0–4.8 kmh for 2 min at 0% grade and there was a 2.5% grade increase every 3 minutes until exhaustion. Peak VO^2 was predicted using ACSM's prediction equations. The results of this study indicated that the use of the ACSM gender and activity specific prediction equations in young adults with DS, peak VO^2 was significantly over-predicted (83.9% DS, and 39.2% non-DS). This would imply that peak oxygen consumption and derived exercise prescriptions must be based

on actual measurements, rather than via ACSM prediction equations. Otherwise, training intensities may be over-predicted and impose possible health risks.

The Six Minute Walk Test (6MWT)

The 6MWT is a practical and inexpensive way to test functional exercise capacity (ATS Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories 2002). It measures the distance walked by participants for a period of six minutes at a pace that is fast without running. Results are considered to be reflective of a person's ability to perform activities of daily living. It has been increasingly used in clinical practice and within research studies as an objective measurement of functional status in patients who are moderate-to-severely impaired with a range of cardiopulmonary conditions (Salzman 2009). It has also been used for adults with cerebral palsy (Andersson, Asztalos and Mattsson 2006), Parkinson's disease (Falvo and Earhart 2009), Alzheimer disease (Ries et al. 2009) and rheumatoid arthritis (Karlsson & Opava 2008).

With regard to individuals with ID, a study carried out by Waninge et al. (2011) found the 6MWT to be a reliable (R=0.92) and feasible tool. The test was administered twice among a group of 47 adults (18 women, 44 ± 10 years; 29 men, 38 ± 11 years) with severe intellectual and sensory disabilities. Vis et al. (2009) administered the test twice with individuals with DS with heart disease (n=29) and without heart disease (n=52). Results indicate no difference in the 6MWT values of those with or without heart disease with authors concluding that it was not a valid tool for assessing cardiovascular fitness among adults with DS. However, it is worth noting that those with heart disease in this study were younger and with lower BMI levels than those without, so to conclude that the 6MWT is not a valid tool to assess cardiorespiratory fitness among people with DS from this study alone is questionable.

In agreement with the previous studies, Casey, Wang and Osterling (2012) found the 6MWT a reliable tool for adolescents and young adults with DS (n=55). In this study each individual performed the 6MWT four times over a two week period. The 6MWT showed good test-retest reliability and increased the walking distance after 2 practice walks emphasizing the need to account for a learning

effect among people with DS. Nasuti, Stuart-Hill and Temple (2013) tested the reliability and validity of the 6MWT for adults with ID (n=13). Each participant performed the graded treadmill test and the modified 6MWT twice. Test–retest reliability of the modified-6MWT was ICC _ .98 and linear regression revealed a correlation between the modified 6MWT distance and the VO^2 peak (R=.84, p<.001). Authors concluded the 6MWT was feasible to administer with this population, and demonstrated acceptable validity and excellent reliability for assessing cardiovascular fitness in adults with ID.

The Rockport Fitness Walking Test (RFWT)

The RFWT consists of participants walking as fast as possible for one mile with a tester walking slightly ahead giving encouragement (Oppewal et al. 2013). The RFWT has been earlier confirmed reliable and valid for adults with ID (R=0.97) (Rintala et al. 1992). Rintala et al. (1992) developed a population specific formula for men with MR (this term was used at the time of test development) and the test was found to be valid. Rintala et al. (1997) cross validated the 1-mile walking test for men with MR. The equations underestimated VO^2 peak value in 74-79% of participants of the study so the test may not be statistically valid for this population and the prediction formula needs further research. Limitations of the study however include a small sample size of 19 males with MR, no randomisation and above average fitness levels of the study participants.

A further study was carried out by Draheim et al. (1999) in the USA with twenty-three adults (10 males and 13 females) with ID. They wanted to look at the effectiveness of further modifying the method of 'one pacer to one walker' (1:1) to 'one pacer to five walkers' (1:5). The intraclass reliability coefficient between the end times from the two 1:5RFWT was R = 0.94. The 1:1RFWT end times also had a correlation of r = 0.90 and r = 0.84 with the end times from the first and second 1:5RFWT, respectively. The intraclass reliability coefficient between the end heart rates from the two 1:5RFWT was R = 0.91. The 1:1RFWT end heart rate also had a correlation of r = 0.91 and r = 0.89 with the end heart rate from the first and second 1:5RFWT, respectively. Draheim et al. (1999) concluded that the 1:5 RFWT could be used to predict aerobic capacity however with the prediction

equations used, overpredicted VO^2 peak for adults with ID, therefore further revision needs to be conducted.

The Multi-stage fitness test

The Multi-stage fitness test requires individuals to run a set distance with increasing speed following instructions from an audio signal. The test ends when a participant falls behind the pace by 5m (Leger 1982). The original test constructed by Leger (1982) uses a 20metre distance however modifications of the test have been developed. Waninge et al., (2011) used an adapted version of 10 metre shuttle run test among a group of 47 adults (18 women, 44 ± 10 years; 29 men, 38 ± 11 years) with severe intellectual and sensory disabilities. Results showed that the shuttle run test is feasible and reliable for measuring aerobic capacity with this population. Similarly, Hilgenkamp, van Wijck and Evenhuis (2012a) found the 10 metre shuttle walk test to be feasible and reliable (0.94) with participants who were older adults (mean 65.9, range 50 – 89 years) with mild to profound ID (n=36).

Waninge et al. (2011) suggests a need for familiarisation testing for adults with severe to profound ID and visual disabilities. However Hilgenkamp, van Wijck and Evenhuis (2012a) contradicts this. The test was performed twice with no learning effect found. Cross-validation of the equation of the 20 m shuttle run test showed poor level of agreement between estimated and measured VO^2 peak, with a possible underestimation or overestimation of measured VO^2 peak by a study carried out by Fernhall et al. (2000) with children and adolescents with ID. These results do not invalidate the 20-m as a walking test for children and adolescents with ID but show that interpreting individual results should be done with caution. The 20m shuttle walk test also relies heavily on intrinsic motivation. This could incur lower than normal performance levels as motivation can often be an issue for people with ID.

As is clearly evident, there are many ways in which to assess the cardiovascular fitness levels of individuals with ID. For the purpose of this study it was determined that the 6MWT, because of its reliability and validity for the study

population, and the convenience of this inexpensive tool, this test was chosen as the most suitable.

Conclusion

This review has highlighted the low PA levels, sedentary behaviour habits and poor physical health of individuals with ID worldwide and showing a critical need for action. SOI has been highlighted as the most popular form of PA for people with ID however it is surprising that no evidence exists on the impact of SOI participation on those involved. The current study wanted to examine the benefits of participating in such an organisation on the physical activity, fitness and BMI levels and BP measurements of people with ID in Ireland. The review has highlighted that different measures have been used to assess PA participation and fitness levels and there are currently no validated self-report questionnaires for people with ID making comparisons of studies difficult. Despite the growing knowledge of evidence of the benefits of physical activity, no evidence exists on the benefits of participation in SOI programmes. The hypothesis of this study is that people who participate in SOI have higher PA levels and better health than those not in SOI. This piece of research provides a unique opportunity to highlight the importance of SOI and to understand the significance of such an organisation in the promotion of PA across the island of Ireland for people with ID.

Methodology

Overview

The focus of this thesis is to report on the physical activity (PA) components of the larger SOPHIE study including physical measurements, fitness testing and PA levels of study participants. The work reported in this chapter includes recruitment of participants, procedures undertaken in data collection, data management and data analysis. In order to gain a better understanding of the activities of those with ID in Ireland, a variety of methodological approaches were used including self-report questionnaire data, fitness testing and objective measures of accelerometry.

Recruitment and Participants

Ethical issue

Ethical approval for this study was obtained from the Ethics Committees of Dublin City University (REC reference: DCUREC/2013/148, approved on the 3rd July 2013), the Office for Research Ethics Committees Northern Ireland (REC reference: 13/NI/0186, approved on the 8th January 2014), St Michael's House (approved 13th November 2013).

On the day of data collection, I verbally went through the participant consent forms which outlined each step of the research process and included an easy read format for people with ID (see appendix A for consent forms). I marked each part of the study in which the participant agreed to take part in and the participant also provided their signature. If the study participant could not write or give verbal consent they were required to mark an 'X' on the consent form in the presence of two members of the research team. Family members signed two consent forms, one on their own behalf and one for the study participant.

All study participants were informed of their right to withdraw at any stage of the process and could refuse to participate in any part of the study. They were informed that all information provided would be confidential. In order to maintain confidentiality each study participant and family member was assigned a unique

identifier code, details of which were held in the master log which was stored separately to the study packs. Only members of the research team had access to hard copies of the data, which were stored in a locked filing cabinet designated for project use only. In order to ensure that participants were eligible for the physical fitness walking test all participants were required to complete a PA readiness questionnaire prior to the test. All participants met the criteria and were deemed ready to complete the submaximal walking test. A nurse qualified in ID was present for the collection of physical data.

Inclusion criteria upon recruitment

- Study participants with ID, ambulant or non-ambulant, over 16 years of age
- A verbal communication skill sufficient to provide information about themselves, or a family member willing to provide this information
- The ability to provide assent or a family member willing to provide informed consent and be registered with a service for people with ID/SOI

Exclusion criteria upon recruitment

- Verbal communication skills not sufficient to provide information about themselves and no family member to provide this information
- Not registered with a service for people with ID/SOI
- Individuals who were without the ability to provide assent or a family member willing to provide informed consent and also individuals who do not have a family member willing/able to take part in the study.

Recruitment

Prior to commencing the SOPHIE study it was anticipated that 500 people would be involved in the study; 200 existing SOI participants and 200 non SOI athlete participants through service provider organisations and 100 participants new to SOI clubs (not more than 3 months since starting a club) to conduct measurements at two time points; at baseline and after 9 months. Over 1,900 participants were invited to participate in the study with only 146 people

participating in the study given the challenges faced in recruitment within this population group. In all cases, participants and family members were met in a location convenient to them i.e. local service provider location or local venues that were appropriate for the data collection requirements.

Recruitment through ID Service Provider Organisations

Service provider organisations who agreed to be involved in the research appointed a link person to correspond with and to ensure that their organisations particular requirements were met. The number of registered service users over 16 years of age was shared. Anonymized or minimal data was shared to allow for recruitment, adhering to data protection laws.

Those attending SOI were identified. A complete list of service users unique identification codes were imputed into an Excel spread sheet and using a Research Randomiser programme, the agreed number of participants from each service were randomly selected, thereby reducing selection bias. Written information about the study, including plain language statement in an easy read format for individuals with ID (including images), frequently asked questions and an information sheet was developed and distributed to interested individuals and their families, either in the post or through service provider staff (see appendix B for study information).

Individuals who take part in SOI who participated in the study were age (±2 calendar years) and sex matched to anonymous identifiers for people who do not take part in SOI, in the same organisation. Often there was more than one match. In this case Research Randomizer software was used to randomly select people with ID who do not take part in SOI to invite to participate. This was a timely process as it involved going back and forth with the link person in the service provider organisation to arrange distribution of study information packs. Often more than five matched individuals were invited, each one week apart, with no success. This method was used in the first two service provider organisations data was collected from, St. Michael's House and Western Care. At Western Care, a strategy was successfully developed whereby all individuals who meet the inclusion criteria would be invited to participate in the research. Participants

would be retrospectively age and sex matched. This method was used thereafter. The method of contact allowed was determined by the service provider organisations; consent was obtained for me to contact service users and their family members or interested service users and their families were invited to contact me.

Verbal information about the study was provided once contact with interested parties was made. On average 2-3 calls were made to each individual invited to take part. If no contact was made after the 4th call, potential participants were removed from the list. Once the low uptake was identified it was decided to contact local media with advertisements placed in local newspapers and a radio interview. Uptake improved when I was able to contact interested individuals however the service provider often insisted that interested individuals must contact me which was often not followed through. The main reasons for declining to participate in the study included; having no family member willing/able to participate with the person with ID, family illness, busy schedules and lack of interest.

Participant recruitment from the NHSCT in NI was unsuccessful. Two individuals expressed interest however given the logistics involved it was deemed not feasible to travel to allow them to participate in the SOPHIE study. Additional resources were put into recruitment in NI including organising transport for study participants with the service provider organisations, however this was unsuccessful.

Table 1 Breakdown of SOI/ non SOI participants who were invited and participated in the study recruited through ID Service Provider Organisations

Service Provider	No. Invited	No. Athletes who participated	No. of non- SOI who participated	Total
St.Michael's House	723	23	11	34
Western Care Association	432	28	10	38
COPE Foundation	500	31	15	46
NHSCT	68	0	0	0
Cheeverstown House	185	6	7	13
Totals:	1,908	98	44	131

Recruitment through Special Olympics Clubs

SOI Regional Developmental Officers (RDO) searched the SOI database for new participants over 16 years who had joined a SOI club within the previous 3 months. Given the logistical challenges of travelling around Ireland for small groups it was decided for each geographical location individuals would only be invited if there were more than five people new to SOI living in that geographical area.

Special Olympics staff contacted the identified individuals that were new to SOI (number unknown). Individuals then consented to have their contact details passed on (n=63). I had to examine the locality of the participants so that I could group at least 5 individuals from the same areas (n=39). Verbal information about the study was provided over the telephone and written information including plain language statement in an easy read format for individuals with ID (including images), frequently asked questions and an information sheet was distributed to interested individuals and their families by post. This resulted in the recruitment of 15 study participants for time point one, and at the follow up session only 4 individuals attended.

The process of searching the SOI database for new participants over 16 years who had joined a SOI club within the previous 3 months was repeated on 3 occasions approximately 3 months apart in order to maximise recruitment. These attempts were unsuccessful at identifying groups of 5 or more people new to SOI from the same locality. Often individuals joined a new club, but had been attending another club for a long period of time and therefore were ineligible to participate as an individual new to SOI.

Table 2 Total number of individuals invited and recruited through SOI clubs

Location	No. agreed to have details shared	No. contacted by research team	No. participated time point 1	No. participated time point 2
Dublin	32	22	6	2
Leinster	17	6	4	2
Ulster	14	11	5	4
Totals:	63	39	15	8

Participants

A total of 1,908 people were invited to partake. All participants were over the age of 16 and had an ID. Males and females were recruited. Participants recruited through services were met at one time point (n=131). Participants recruited through SOI programmes accounted for 15 athletes at time point 1 and only 4 athletes returned at time point 2.

Procedures

Pilot testing

A nurse qualified in ID was present to ensure minimisation of potential sources of error in the physical measures and questionnaire administration, and a qualified dietician provided training for anthropometry measurements. They also provided training on conducting interviews with people with ID. A pilot study was conducted with a female basketball team having players with ID (n=10) and their family members. From the feedback provided by the team and their families, along with suggestions from the research team, amendments were made. It was felt that the questionnaire was too long and in places hard to comprehend, the structure and order of the physical measures stations were also changed for data collection to ensure that going forward we worked in the most time efficient way and that stations flowed better. It was also decided that one to one support was needed with each participant/family member that took part in the study as it was taking too long going between groups. This meant that I could only invite smaller groups to each data collection event but also meant that better quality of data was being recorded.

Participant Questionnaire

The survey questionnaire was the main data collecting instrument for this study (see Appendix C for participant questionnaire). As there is no validated instrument used for this population, the questionnaire used was an adapted version of the SLAN 2007 (Ward 2009). This is a survey on the lifestyle, attitudes and nutrition in Ireland, so that a comparison can be made between the general population of Ireland and the study participants. The current questionnaire was split into 8 sections; basic information about the study participant, general health, PA levels, diet and nutritional status, smoking status, alcohol intake, family, social network and neighbours and general household information. The PA section of the questionnaire included questions from the short form International Physical Activity Questionnaire (IPAQ). To help create a more user friendly

questionnaire and to aid understanding for the study participants, diagrams were added to the PA section. In this study PA was classified as strenuous (sweating, out of breath, heart beating faster), moderate (a little out of breath but heart not beating faster) or mild (minimal effort such as gentle walking). Individuals with ID were encouraged on all occasions to answer questions themselves but assistance from family members was sought when required. The level of support required varied from individual to individual in this heterogeneous population.

The Six-Minute Walk Test

The 6MWT is a widely accepted reliable and valid tool for measuring functional exercise capacity in people with disabilities (Vis et al, 2009; Waninge et al. 2011; Casey, Wang and Osterling 2012; Nasuti, Stuart-Hill and Temple 2013). It involves walking back and forth as quickly as possible on a flat, hard surface, along a straight path for 6 minutes. Variations in length of corridor have become apparent with some studies using 20-50m length areas (American Thoracic Society, 2002). The 6MWT has been investigated for use as a predictor of morbidity and mortality (Alahdab et al. 2009) and has been used with clinical and healthy populations to assess functional capacity and cardiovascular fitness (Nasuti, Stuart-Hill and Temple 2013). The 6MWT is inexpensive, and is easy to set up and to follow. Standardised testing procedures published by the American Thoracic Society were adhered to during data collection along with modifications including 1:1 pacer and 15s encouragement which were validated by Nasuti, Stuart-Hill and Temple (2013) who conducted the 6MWT with adults with ID. The use of a 20metre flat surface was used throughout the study mainly for logistic purposes. Larger cones were placed at the start and end point of each lane with smaller cones laid out every 2 metres. Lead researcher called out instructions while a research team member accompanied participants on the walk. Pace was to be set by the participant, not the researcher (see Appendix D for walk test instructions). Total distance was recorded on the individual's data collection sheet (see Appendix E for data collection sheet).

Anthropometric Measurements

The WHO STEPwise approach to Surveillance (STEPS) is a simple, standardized method for collecting, analysing and disseminating data in WHO member countries" (World Health Organisation 2014). Section 3: Guide to Physical Measurements (Step 2) was adapted to suit the study population. All measurements were taken twice and the mean was used for analysis (see Appendix F for protocols). Height (m) was measured using a Leicester Height Measure to the nearest 2 decimal places. Weight (kg) was measured to the nearest 0.1 kg using calibrated TANITA HD-305 scales and TANITA WB-100MA. Participants BMI was calculated using the Quetelet formula, (weight (kg)/ height^2 (m^2)). Waist circumference was measured to the nearest 0.1 cm using an anatomical measuring tape. Measurements were taken at the narrowest point from the anterior view (or halfway between the rib cage and the superior iliac crest) at the end of a gentle expiration, with participants in a standing position.

Accelerometers

Participants were invited to wear an Actigraph (GT3X) accelerometer over the right hip on an elasticized belt for the 7 days after data collection day. A daily diary was completed by participants and carers to distinguish periods when the participant did not wear the accelerometer, e.g. when bathing. Such non-wear time was then excluded from the analysis. Participants were asked to wear the device while they were awake and to take it off while swimming/bathing or doing contact sports where the device could get damaged. Monitors were collected by study investigators either at the home of participants or in their service provider. Data was recorded in 10 second epochs for up to 1 week. Raw accelerometer counts were downloaded using ActiLife software (version 6.11.3) and used to calculate the time spent in light, moderate and vigorous intensity PA and sedentary behaviour.

Data Management

Data was locked and stored securely at all times. Each participant was given a unique identification code and all data obtained was identified using this code. Consent forms and a master log linking participant identification codes with confidential data were stored securely in a separate location.

Data Processing

Accelerometer data was collected from 107 participants, however data for participants with four or more valid days are described throughout (n=80). For the analysis presented on accelerometry data, a valid day was defined as having 10 or more hours of wear time. Non wear time was defined by an interval of at least 60 consecutive minutes of zero activity counts (Troiano et al. 2008). Counts of minutes of sedentary, light and moderate and vigorous intensity PA were calculated using Freedson adult cut-points (Freedson, Melanson and Sirard 1988). Minutes of PA accumulated per level of activity were summed. In order to get average minutes per day, this figure was then divided by the number of calendar days participants wore the monitor.

Participants were divided into 3 groups according to their age; Group 1: 16-24.99yrs; Group 2: 25-44.99yrs; Group 3; 45-64.99yrs. Blood pressure was classified into 6 groups following the Irish Heart Foundation classification: normal, pre hypertension, high stage 1, high stage 2 and hypertensive crisis. BMI was categorised according to WHO (2008): normal weight18.5-24.99kg/m², underweight 15-18.49kg/m², overweight 25-29.99kg/m² and obese BMI >30kg/m².

A Health Profile score was calculated for each participant by creating a new variable consisting of summed scores from BMI, BP, meeting ≥ 30 mins MVPA daily by self-report, and distance walked in the submaximal fitness test. BMI categories were each given a value; normal weight (1), underweight (.5), overweight (.5) and obese (0). BP categories were scored as normal (1), prehypertension (.66), high stage 1 (.33), high stage 2/hypertensive crisis (0), meeting MVPA guidelines was scored as healthy (1), and unhealthy (0). Distance covered in the 6MWT was divided into four quartiles (Q); starting with the

furthest distance and scored as Q4 (1), Q3 (.66), Q2 (.33) and Q1 as 0. The optimal score for each of the four categories was 1 so when summed together, the health profile score ranged from a minimum of 0 (the most unhealthy) to a maximum score of 4 (the most healthy).

Data analysis

Self-report questionnaire data was entered into Microsoft Excel. When all relevant data was entered each record was manually checked for errors. All data from self-report questionnaires, anthropometry measurements and accelerometer data were analysed using SPSS version 21 with alpha set at $p < 0.05$. Where participants had incomplete data for a given variable, participants were excluded from analysis of this variable only. Descriptive statistics were calculated via means, standard deviations, minimums, maximums and percentages where appropriate. One-way between groups ANOVA's were used to investigate differences in MVPA accelerometer scores across the three age categories. A series of two-way between groups ANOVA's were conducted to explore the impact of SOI participation and gender on; MVPA questionnaire and accelerometry data, fitness levels measured by the distance walked in a Modified Six Minute Walking Test, and differences in health profiles of SOI/non SOI participants.

Results

This section will provide the main findings of the current study. Descriptive and anthropometric characteristics of participants, MVPA by accelerometry and self-report and finally physical fitness and Health Profile scores will be included. Of the 146 participants, 8% of the total invited participated in the research. Some reasons for non-participation included other family commitments, venues unsuitable to travel to, no family members present to attend sessions, elderly parents unable to attend.

Descriptive and anthropometric characteristics

Of the 146 participants involved in the study, 101 (69%) were SOI athletes and 45 (31%) were non SOI participants. Of these 146 participants, 58.2% were male and 42.8% were female with a mean age of 33.01 ± 11.09 years. Just under half (47.5%) of the population were considered to have a mild ID, 46.1% were considered moderate and 6.4% were deemed severe (see Table 4). Information on gender, age, BMI and BP of participants overall, and by SOI participation status are given in Tables 3 and 4 below. Table 5 gives an overview of minutes of sedentary, light and MVPA (by accelerometry and self-report), percentage meeting the 30-minute MVPA guideline (see also figure 1), and physical fitness score overall, and by SOI participation status. Results of the one-way between groups ANOVA demonstrated that there was no significant difference in MVPA accelerometer scores across the three age categories; $F(2, 77) = .87$, $p = .422$. Age did not have any significant role in any other aspect of the study.

Table 3 Descriptive statistics of mean (SD) age, BMI and Health Profile score of both SOI and non SOI groups

		Total population	SOI athletes	Non SOI
Age (years)	n	146	101	45
	Mean (SD)	33.01 (11.09)	31.39 (10.78)	36.65 (11.05)
BMI (kg/m^2)	n	137	97	40
	Mean (SD)	29.3(7.46)	28.8(6.2)	30.7(9.9)
Health Profile	n	86	66	20
	Mean (SD)	2.06(.82)	2.18 (0.81)	1.64 (0.70)

Table 4 Frequency table of study participants

	Total pop. (n)	%	SOI (n)	%	Non SOI (n)	%
Gender						
Male	85	58.2	64	63.4	24	46.7
Female	61	42.8	37	36.6	27	53.3
Age categories						
16-29years	43	29.5	34	33.77	9	20.0
30-44years	77	52.7	52	51.5	25	55.6
45-64years	26	17.8	15	14.9	11	24.4
Level of ID						
Mild	67	47.5	51	52.6	16	36.4
Moderate	65	46.1	42	43.3	23	52.3
Severe	9	6.4	4	4.1	5	11.4
BMI categories						
Underweight	4	2.9	2	2.1	2	5
Normal	35	25.5	30	30.9	5	12.5
Overweight	37	27	24	24.7	13	32.5
Obese	61	44.5	41	42.3	20	50
BP categories						
Normal	58	39.7	45	46.6	13	28.1
Prehypertension	54	37	40	39.6	14	31.1
High BP Stage 1	2	1.4	2	2	0	0
High BP Stage 2	3	2.1	3	3	0	0
Hypertensive Crisis	1	.7	1	1	0	0

MVPA by accelerometry and self-report

As can be seen form Table 5 below, with regard to accelerometry data, SOI participants recorded a higher mean minutes of MVPA daily (52.6 ± 34.3mins) than non SOI participants (45.3 ± 29.7 mins). Results of a two-way between groups ANOVA show that this difference was not significant; the interaction effect between gender and SOI status was non-significant, F (2, 76) = .159, p = .691), and there was no main effect for either gender, F (2, 76= .936, p= .336) or SOI status (2, 76= .384, p= .537). When self-report minutes of MVPA were considered, again SOI recorded higher mean minutes of MVPA daily (28.8± 32) than non-SOI participants (9.7± 22). Results of a two-way between groups ANOVA indicated that there was no significant interaction between gender and SOI status F (2, 117) = 1.90, p = .171). There was a statistically significant main effect for SOI status F (2, 117) = 10.19, p = .002) with a medium effect size (partial eta squared = .080).

Table 5 Mean (SD) Physical Activity and Fitness data

		Total pop.	SOI athletes	Non SOI
Physical Activity – Accelerometer (per day)				
Sedentary (mins)	n	80	61	19
	Mean(SD)	679.5(182.1)	695.4(179.7)	628.4(185)
Light (mins)	n	80	61	19
	Mean(SD)	227.2(87)	233(81.2)	208.5(102.4)
MVPA (mins)	n	80	61	19
	Mean(SD)	50.9(33.3)	52.6(34.3)	45.3(29.7)
Physical Activity – Self Report (per day)				
Light (mins)	n	136	94	42
	Mean(SD)	25.6(38.4)	25.7(38.5)	25.3(38.4)
Moderate (mins)	n	130	89	41
	Mean(SD)	18.9(32.3)	23.6(35.1)	8.5(21.7)
MVPA (mins)	n	121	80	41
	Mean(SD)	22.3 (30.6)	28.8(32)	9.7(22)
Vigorous (mins)	n	128	86	42
	Mean(SD)	5.5(10.2)	7.5(11.3)	1.3(5.4)
Met MVPA guidelines				
	n	121	80	41
	Yes	29.8%	40%	9.8%
	No	70.2%	60%	90.2%
Six Min Walking Test Distance (metres)				
	n	108	85	23
	Mean(SD)	518.5(110.6)	541(103)	436(100.6)

Physical fitness and Health Profile score

Similarly, with reference to the physical fitness data, results indicate that the interaction effect between gender and SOI status was not significant, F (2, 104) = .787, p = .377), but there was a significant main effect for SOI status, F (2, 104) = 16.34, p = .000, partial eta squared = .136). As can be seen from Table 3, this significant effect points to a significantly greater distance score of SOI participants (541± 103 metres) compared to non-SOI participants (436± 100.6 metres) (see also figure 2). Results of the two-way ANOVA investigating difference in health profile show that there was no significant interaction between gender and SOI status, F (2, 82) = 1.33, p = .253), but that again there was a significant main effect for SOI status, F (2, 82) = 6.4, p = .013), with SOI participants scoring a significantly higher overall health profile (2.18 ± 0.81) than non-SOI participants (1.64 ± 0.70).

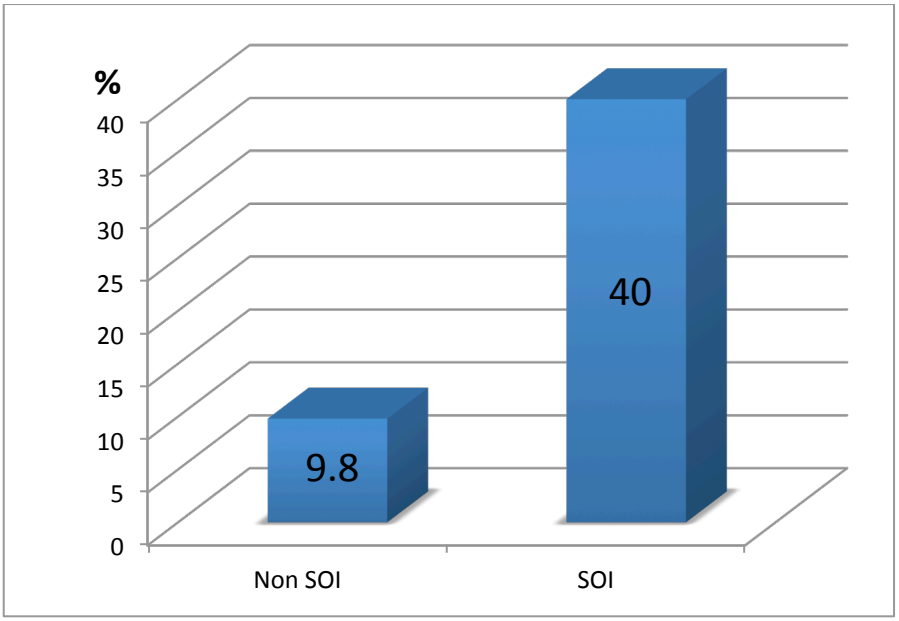


Figure 1: Percentage of study participants meeting 30 minute MVPA guidelines as per self-report

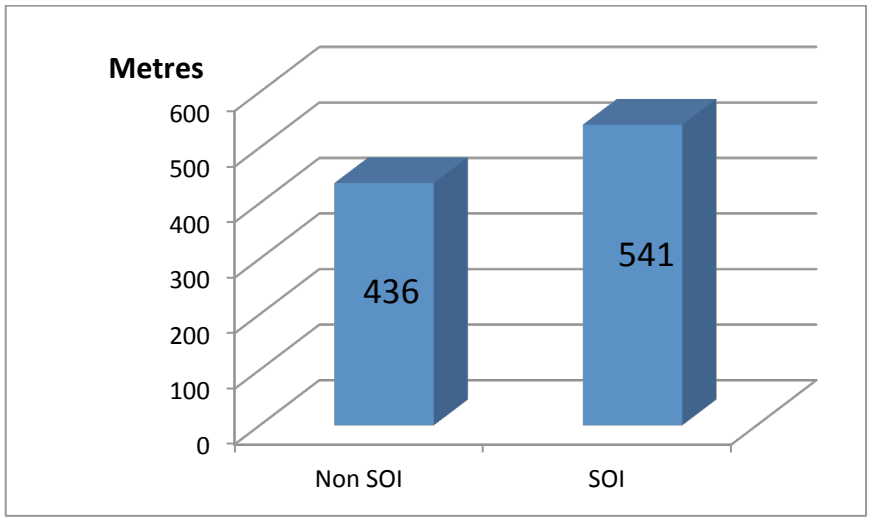


Figure 2: Distance covered (meters) of the Six Minute Walk test

Discussion

The purpose of this study was to compare the PA habits and physical fitness levels BP and BMI of adults with ID, including those both in SOI and not participating in SOI programmes. In this chapter I will discuss the findings relative to the study objectives including sedentary behaviour, MVPA by self-report and accelerometry, physical fitness testing, BMI, BP and health profile scores. I will also make reference to previously examined research.

Sedentary Behaviour

Participants in the current study spent most of their waking hours sedentary (71%), accumulating a mean 679.5 ± 182.1 sedentary minutes per day. These findings are consistent with previous research in relation to sedentary behaviour and people with ID (Temple and Walkley 2003; Philips and Holland 2011; and Messent, Cooke and Long 1999) although sedentary behaviour is a common problem across all populations. Those with ID tend to accumulate more time in sedentary behaviour compared to the general population. For example, Jans et al (2007) found that Dutch workers (n=7720) spent on average 420 minutes a day sitting, one third of which was at work. Similarly, in a sample of 576 men and women aged 40 –74 years from Shanghai, accelerometer data revealed that they accumulated an average 509 minutes in sedentary behaviour (Peters et al. 2010).

MVPA by self-report

The current study indicates that only 29.2% of the population self-reported sufficient MVPA minutes to meet the >30mins MVPA guidelines (American College of Sports Medicine 2011). While no other Irish studies have been identified using similar methodologies for people with ID, the SLAN 2007 study (Ward 2009) used a similar self-report method as a means of gathering data on MVPA in a representative sample of the general population. Fifty five percent of the general population reported being 'physically active', meaning that they completed exercise or sport 2-3 times per week for a minimum of 20 minutes or engaged in more general activities, like walking, cycling or dancing, 4-5 times per week accumulating to at least 30 minutes per day. In a study in Canada with 103 adults with mild to moderate ID aged 19-65 years, 64.1% reported that they

participated in five or more bouts of MVPA per week, however, only 17.5% of participants accrued the recommended duration of 30 minutes MVPA per day according to pedometer data (Stanish and Draheim, 2005).

MVPA by accelerometry

With regard to accelerometry data, those in SOI accumulated 52.6 ± 34.3 minutes MVPA per day in the current study compared to 45.3 ± 29.7 for non SOI participants. These findings are not consistent with previous research carried out with people with ID, who largely report lower levels of MVPA within this population when measured using accelerometry. In the USA, adults with ID (n=44) only accumulated 7.73 ± 24.21 minutes of MVPA per day and 47.6% of the participants averaged zero minutes of MVPA per day (Bodde et al. 2013). Similarly, Frey, Buchanan and Sandt (2005) found that in a sample of twenty two adults with ID, MVPA averaged 19.7 ± 17.6 minutes per day by use of accelerometry. Troiano et al. (2008) conducted an evaluation of PA in the USA using accelerometry with a representative sample of the general population. Findings revealed that adults were averaging 6-10 minutes MVPA per day across the age of 16-69years. Although the current study suggests that those with ID accumulate more minutes MVPA than previous research in the general and ID population, perhaps with a larger sample size and a greater representation of people with severe and profound ID, results may have been different.

Within the current study, MVPA was measured in two separate ways; by use of accelerometry and by self-report questionnaire. Unfortunately, fewer participants consented to wear the accelerometer and so less data is available on this element of the study. Though the pattern is similar in both measures with SOI participants accumulating more mean minutes of MVPA per day than non SOI participants, the large differences between accelerometer (50.9 ± 33.3 mins) and self-report (22.3 ±30.6 mins) measured MVPA must be noted. It is unusual for accelerometer activity to be higher than self-report activity with self-reporting more commonly seen to overestimate PA (van de Mortel 2008; Klesges et al. 1990). Obviously, the low numbers (n=80) in the accelerometer analysis is a limitation in this study. It must be considered however, whether the cut point thresholds used which were developed for the general population (Freedson,

Melanson and Sirard 1998), are relevant and appropriate for this population. The high levels of accelerometer measured activity found within this population sample may have also been influenced by the fact that people with severe and profound ID were underrepresented in this study population thereby potentially favouring a more active sample. Robertson et al. (2000) suggest levels of inactivity have been associated with more severe levels of ID. Those with more severe ID's have greater limitations in completing activities of everyday living (Jones et al. 1999). Caution should be exercised in generalising the current findings due to the limitations of a small sample size as well as the lack of severe and profound participants with ID.

Self-Report

Individuals with ID were encouraged on all occasions to answer the self-report questions themselves and assistance from family members was sought when required. The level of support required varied from individual to individual in this heterogeneous population. In the majority of cases, however family members were needed to supply a great deal of information on behalf of participants. Issues with conducting interviews and use of self-reporting for the ID population have been reported in the literature (Finlay and Lyons 2001; Stalker 1998). In order to gain comprehensive information, it is sometimes not merited to gain this directly from the individual themselves. For example, a common problem with self-reporting in the ID population is questions with content about time and providing a judgement of frequency (Booth and Booth 1994). In the current study participants were asked about how often they took part in different forms of activity. Self-reporting of activities was low; this may be because they were inactive but may also be a product of not being able to relay this type of information correctly. However more consideration needs to be placed on creating validated questionnaires and highlighting specifically the population for which the instrument is designed.

Accelerometry

Given the low sample size in the non SOI group who's accelerometer data fit the inclusion criteria (n= 19), and the subsequent impact on power, it is perhaps unsurprising that no significant difference in MVPA level by accelerometer was

found in the current study, despite the descriptive statistics suggesting higher accumulation in the SOI group overall. When considering self-report minutes of MVPA, those in SOI (28.8 ± 32) were found to be significantly more active (p= .002) than non SOI participants (9.7 ± 22). In the current study, self –report data suggests that a large number of participants (70.2%) overall do not accumulate sufficient minutes of MVPA to meet the >30 minute per day MVPA guideline for promoting better health. Of the two groups, 40% of SOI participants reported meeting the guidelines, compared to only 9.8% non SOI participants. Findings are consistent with the TILDA report in 2014, which also showed that 70% of adults with ID reported engagement in low levels of activity, levels not likely to result in health benefits (McCarron et al., 2014). This compares with 59% of the general population who reported not meeting the MVPA guidelines in Ireland in the SLAN 2007 report (Ward 2009).

Physical Fitness Testing

Physical fitness was measured using a modified sub maximal 6MWT. The mean distance covered in the current study was 518.5m ± 110.6, with SOI participants walking a greater distance significantly (541 ± 110.6, p=.000) than non SOI participants (436 ± 100.06). These compare to a study with a healthy older adult population who reported the mean distance score as 631m ± 93 (Troosters et al. 1999). A study with people with heart failure reported the mean distance as 419m ±120 (Faggiano et al. 1997), and a study with people with chronic obstruction pulmonary disease (COPD), the mean distance was reported as 369m ± 18 (Onorati et al. 2003). A study with participants who had severe multiple disabilities reported the mean distance as 389m ± 107 (Waninge et al. 2011). With the population in the current study being people with mostly mild and moderate ID it is not surprising that they scored higher distances than those with severe ID, COPD and heart failure as these populations generally experience additional health issues which may impact their physical capabilities in the walking test. It would be expected for those in the current study to score lower levels than the general population as people with ID are less physically active than the general population which should in turn impact on physical fitness scores.

Certain differences in test protocols must be considered when comparing between studies using the 6MWT which may all have the potential to affect walking distance of study participants for example; familiarisation sessions, pacers, level of encouragement and varying distances used. Familiarisation sessions have been recommended for people with ID (Rintala, McCubbin and Dunn 1995, Waninge et al. 2011) with Casey, Wang and Osterling (2012) finding an increase in walking distance after 2 practice walks. This emphasises the need to account for a learning effect among people with disabilities. It is important to note that this was not feasible in the current study which may be seen as a limitation and as such the figures presented may underestimate to a small extent the true distance capability of individuals.

Consistent with previous research for people with ID, pacers and additional encouragement were used in the current study (Beets et al. 2005; Rintala et al. 1992; Nasuti, Stuart-Hill and Temple 2013; Waninge et al. 2011). In order to prevent affecting the distance walked, the protocol of Waninge et al. (2011) was followed, where individuals with ID self-paced with pacers walking beside them. Encouragement was also given every 15 seconds in accordance with the modified 6MWT protocol set out by Nasuti, Stuart-Hill and Temple (2013).

The distance used in the walking test can vary across studies also. The American Thoracic Society (2002) suggests a 30metre flat surface for optimal performance as shorter distances increases the amount of turns needed so therefore potentially negatively affecting the distance walked. However findings from a multicentre study revealed no significant effect on walking distance of straight courses ranging from 15-50metres (Weiss et al. 2000). The current study used a 20 metre flat surface for logistical purposes. The modified 6MWT is a straightforward and practical test with minimal time, space, measurement, and equipment requirements.

Blood Pressure

In relation to BP only 4% of the participants in the current study had a BP measurement in the hypertensive range. While acknowledging the limitation of single measurement, it is surprising that the majority of this population had BP in the normal or pre-hypertensive range because individuals who present as

overweight or obese, like the majority of this study sample, are considered more at risk of having hypertension (Sturm 2002). These findings are consistent with findings from the TILDA study however, which found that rates of hypertension were 50% lower in individuals with intellectual disabilities (18%) than the general population (37%) (McCarron et al. 2014). The findings from the current study are promising in that having a lower BP may be associated with the high physical activity levels of individuals in the study. Previous research has shown that like the general population, physical activity can reduce BP for individuals with intellectual disabilities (Calders et al. 2011; Pett et al. 2013).

BMI

The alarming figure of 71.5% of the study population being classified as overweight or obese, is consistent with findings from the IDS- TILDA study. This found that 77.3% of adults over 40 years of age with ID in Ireland, who had weight and height measurements taken, were overweight or obese (McCarron et al. 2014). These high figures are not specific to Ireland but are evident worldwide (Moran et al. 2005; Fisher 2004; Yamaki 2005). There was also a higher prevalence of overweight and obesity in the study population compared to the general population (SLAN 2007 report), of whom 61% are overweight or obese (Ward 2009). This highlights the need for more attention to be placed on health promotion opportunities such as SOI and other sports/ physical activity opportunities and healthy eating promotion methodologies to be warranted in Ireland.

Health Profile Score

Within the current study, 86 participants provided information on all four categories that made up the health profile scores including BMI, BP, fitness test and meeting the recommended >30 minutes MVPA per day. This score is considered meaningful in that it could potentially be an important indicator of overall health and quality of life of individuals with ID, as such indicators can gather comparable health information and thus identify health inequalities within this population (Walsh 2008). It is worthwhile noting that those in SOI had a significantly ($p=.013$) more positive health profile score (2.18 ± 0.81) than those

not in SOI (1.64 ± 0.70). To the authors knowledge there are no similar studies available in the literature to make direct comparisons.

Similarly, to the author's best knowledge, no studies have been published investigating the impact of SOI participation on PA and fitness levels of individuals with ID in Ireland. Studies have looked to examine the effect of PA on different aspects of health in persons with ID (Rimmer et al. 2004; Escobar et al. 2013; Bartlo and Klein 2011) and have consistently shown a positive impact of PA participation in health and well-being. For example, Pett et al. (2013) conducted a 12-week healthy lifestyle intervention with 30 obese home-dwelling young adults with ID. The intervention consisted of health education and PA sessions which took place twice per week (1.5 hours/session) for a total of 36 hours. Compared with controls, at a 3 month follow up, the intervention group demonstrated significant improvements in BP, weight, and balance ($p = .05$). To surmise, PA participation has been shown to have a positive physical health impact on the lives of people with ID.

Conclusion

In conclusion, the results presented in the current study are consistent with the literature in showing that people with an intellectual disability are more likely to be overweight and obese, report lower physical activity levels than recommended for health, and have lower fitness levels than the general population. Findings show that participants in SOI accumulate significantly more minutes of moderate to vigorous physical activity per day, have higher fitness levels, and more positive health profile scores than persons with intellectual disabilities that do not participate in SOI. The mission statement of SOI is to provide all individuals with an intellectual disabilities continued opportunities to develop physical activity fitness, demonstrate courage, experience joy and participate in the sharing of gifts, skills and friendship with their families, other Special Olympic athletes and the wider community. SOI is one of the most favoured forms of physical activity for people with intellectual disabilities in Ireland, and as such findings from the current study are very promising as they highlight the potential SOI has on making a difference to the physical health, and subsequently the overall health and wellbeing of people with intellectual disabilities.

While it is clear from my data, SOI participants have gained more minutes of moderate to vigorous physical activity per day, have higher fitness levels, and more positive health profile scores than persons with intellectual disabilities than those who do not participate in SOI causality cannot be determined as it could be argued that people who take part in SOI take part because they are fitter, and more physically active. Further longitudinal research is warranted to determine whether those with increased physical activity and better health profiles opt to participate in SOI, or whether this increased physical activity and better health profile and is as a result of participation.

Limitations of the study

In the current study sample size was lower than previously anticipated (n=146) which was primarily due to recruitment challenges. There was also a lack of representation of people with severe and profound ID. However, this is not

something that is new to this field of research. Recruitment can be challenging in this hard to reach population. As the main focus of the study was on SOI participants and recruitment resulting in mainly people with mild to moderate ID's, generalizability of findings to the boarder ID population is limited.

Recommendations for future research

- The use of 1:1 pacers in the 6MWT adds to the staffing demand therefore research should examine the impact of removing pacers or increasing the participant-to-staff pacer ratio.
- Research, with a representative sample of ID participants, is essential to 1) further examine the PA habits and fitness levels of adults with ID ranging from mild to profound ID and 2) further assess the health impact of SO participation for the ID population.
- The health profile score or a similar tool may be useful to assess and compare the health status of individuals with disabilities and other groups. It may highlight inequalities in health and therefore be useful when planning interventions and indeed evaluating their effectiveness. Research is also needed to obtain the most effective objective measure of PA for individuals with ID. Consideration also needs to be placed on creating validated questionnaires for self-reporting within the heterogeneous ID population, highlighting specifically the population for which the instrument is designed.

References

Allender, S. Cowburn, G. and Foster, C. 2006. Understanding participation in sport and physical activity among children and adults: A review of qualitative studies. *Health Education Research,* 21(6), pp.826-835.

Alahdab, M.T. Mansour, I.N. Napan, S. and Stamos, T.D. 2009. Six minute walk test predicts long-term all-cause mortality and heart failure rehospitalization in African-American patients hospitalized with acute decompensated heart failure. *Journal of Cardiac Failure,* 15(2), pp.130-135.

American Association of Intellectual and Developmental Disabilities 2013. *Definition of intellectual disability* [Online]. Available from: http://aaidd.org/intellectual-disability/definition#.VW17hs9VhHw [Accessed 06/02 2015].

American College of Sports Medicine 2013. *ACSM's guidelines for exercise testing and prescription.* Lippincott Williams & Wilkins.

American College of Sports Medicine 2011. *ACSM, AHA support federal physical activity guidelines: ACSM in the news.*

American Psychiatric Association 2013. *Diagnostic and statistical manual of mental disorders: DSM-5.* 5th ed. Washington DC: American Psychiatric Publishing.

Andersson, C. Asztalos, L. and Mattsson, E. 2006. Six-minute walk test in adults with cerebral palsy. A study of reliability. *Clinical Rehabilitation,* 20(6), pp.488-495.

Andrews, W. 2005. *Stress Control for Peace of Mind.* New York: Barnes & Noble Books.

ATS Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories. 2002. ATS statement: Guidelines for the six-minute walk test. *American Journal of Respiratory and Critical Care Medicine,* 166(1), pp.111-117.

Bailey, R.C. Olson, J. Pepper, S.L. Porszasz, J. Barstow, T.J. and Cooper, D. 1995. The level and tempo of children's physical activities: An observational study. *Medicine and Science in Sports and Exercise,* 27(7), pp.1033-1041.

Barr, M. and Shields, N. 2011. Identifying the barriers and facilitators to participation in physical activity for children with down syndrome. *Journal of Intellectual Disability Research,* 55(11), pp.1020-1033.

Bartlo, P. and Klein, P.J. 2011. Physical activity benefits and needs in adults with intellectual disabilities: Systematic review of the literature. *American Journal on Intellectual and Developmental Disabilities,* 116(3), pp.220-232.

Beets, M.W. Pitetti, K. H. and Fernhall, B. 2005. Peak heart rates in youth with mental retardation: PACER vs. treadmill. *Pediatric Exercise Science,* 17(1), pp.51-61.

Biddle, S.J. and Mutrie, N. 2007. *Psychology of physical activity: Determinants, well-being and interventions.* Routledge.

Blinde, E.M. and McClung, L.R. 1997. Enhancing the physical and social self through recreational activity: Accounts of individuals. *Adapted Physical Activity Quarterly,* 14(4), pp.327-344.

Bodde, A.E. and Seo, D. 2009. A review of social and environmental barriers to physical activity for adults with intellectual disabilities. *Disability and Health Journal,* 2(2), pp.57-66.

Bodde, A.E. Seo, D.C. Frey, G.C. Van Puymbroeck, M. and Lohrmann, D.K. 2013. Correlates of moderate-to-vigorous physical activity participation in adults with intellectual disabilities. *Health Promotion Practice,* 14(5), pp.663-670.

Bohannon, R.W. and Andrews, A.W. 2011. Normal walking speed: A descriptive meta-analysis. *Physiotherapy,* 97(3), pp.182-189.

Bohannon, R.W. Bear-Lehman, J. Desrosiers, J. Massy-Westropp, N. and Mathiowetz, V. 2007. Average grip strength: A meta-analysis of data obtained

with a jamar dynamometer from individuals 75 years or more of age. *Journal of Geriatric Physical Therapy (2001),* 30(1), pp.28-30.

Booth, T. and Booth, W. 1994. The use of depth interviewing with vulnerable subjects: Lessons from a research study of parents with learning difficulties. *Social Science & Medicine,* 39(3), pp.415-424.

Bradley, A. 1996. Healthy body, healthy Mind. *American Fitness,* 14(4), pp.24.

Bravata, D.M. Smith-Spangler, C. Sundaram, V. Gienger, A.L., Lin, N., Lewis, R., Stave, C.D., Olkin, I. and Sirard, J.R. 2007. Using pedometers to increase physical activity and improve health: A systematic review. *Jama,* 298(19), pp.2296-2304.

Brooker, K. Mutch, A. McPherson, L. Ware, R. Lennox, N. and van Dooren, K. 2015. "We can talk while we're walking": Seeking the views of adults with intellectual disability to inform a walking and social-support program. *Adapted Physical Activity Quarterly,* 32(1), pp.34-48.

Butler, P. Green, J. A. Boyd, I. L. Speakman, J. R. 2004. ESSAY REVIEW measuring metabolic rate in the field: The pros and cons of the doubly labelled water and heart rate methods. *Functional Ecology,* 18pp.168-183.

Calders, P. Elmahgoub, S. Roman de Mettelinge, T. Vandenbroeck, C. Dewandele, I. Rombaut, L. Vandevelde, A. and Cambier, D. 2011. Effect of combined exercise training on physical and metabolic fitness in adults with intellectual disability: A controlled trial. *Clinical Rehabilitation,* 25(12), pp.1097-1108.

Carmeli, E. Zinger-Vaknin, T. Morad, M. and Merrick, J. 2005. Can physical training have an effect on well-being in adults with mild intellectual disability? *Mechanisms of Ageing and Development,* 126(2), pp.299-304.

Casey, A.F. Wang, X. and Osterling, K. 2012. Test-retest reliability of the 6-minute walk test in individuals with Down Syndrome. *Archives of Physical Medicine and Rehabilitation,* 93(11), pp.2068-2074.

Caspersen,C. Powell, K. Christenson, G. 1985. Physical activity, exercise, and physical fitness: Definitions and distinctions for health-related research. *Public Health Rep,* 100(2), pp.126-131.

Castagno, K.S. 2001. Special Olympics Unified Sports: Changes in male athletes during a basketball season. *Adapted Physical Activity Quarterly,* 18(2), pp.193-206.

Climstein, M. Pitetti, K. Barrett, P. and Campbell, K. 1993. The accuracy of predicting treadmill VO^2 max for adults with mental retardation, with and without Down's Syndrome, using ACSM gender-and activity-specific regression equations. *Journal of Intellectual Disability Research,* 37(6), pp.521-531.

Cooper, S. Melville, C. Morrison, J. 2004. People with intellectual disabilities: Their health needs differ and need to be recognised and met. *BMJ: British Medical Journal,* 329(7463), pp.414-415.

Darrah, J. Wessel, J. Nearingburg, P. and O'Connor, M. 1999. Evaluation of a community fitness program for adolescents with Cerebral Palsy. *Pediatric Physical Therapy,* 11(1), pp.18-23.

Department of Health and Children, Health Service Executive 2009. *The national guidelines on physical activity for ireland.*

Dixon-Ibarra, A. Lee, M. and Dugala, A. 2013. Physical activity and sedentary behavior in older adults with intellectual disabilities: A comparative study.

Dowling, S. Hassan, D. McConkey, R. and Breslin, G. 2012. Examining the relationship between physical activity and the health and wellbeing of people with intellectual disabilities: A literature review. Special Olympics Ireland and the University of Ulster. *Special Olympics Ireland,*

Draheim, C.C. Williams, D.P. and McCubbin, J.A. 2002. Prevalence of physical inactivity and recommended physical activity in community-based adults with Mental Retardation. *Journal Information,* 40(6),

Draheim, C.C. Laurie, N.E., McCubbin, J.A. and Perkins, J.L. 1999. Validity of a modified aerobic fitness test for adults with Mental Retardation. *Medicine and Science in Sports and Exercise,* 31(12), pp.1849-1854.

Einhorn, H. and Hogarth, R. 1981. Behavioral Decision Theory: Processes of judgment and choice. *Journal of Accounting Research,* 19(1), pp.1-31.

Emerson, E. McConkey, R. Walsh, P.N. and Felce, D. 2008. Editorial: Intellectual disability in a global context. *Journal of Policy and Practice in Intellectual Disability,* 5(2), pp.79-80.

Emerson, E. Felce, D. and Stancliffe, R.J. 2013. Issues concerning self-report data and population-based data sets involving people with Intellectual Disabilities. *Intellectual and Developmental Disabilities,* 51(5), pp.333-348.

Escobar, L.T. Sanders, M.E. Lawson, D. and Benitez, C.B. 2013. A case study: Mobility and health impact of an aquatic fitness program for a woman with intellectual and physical disabilities. *International Journal of Aquatic Research & Education,* 7(2),

Esliger, D.W. and Tremblay, M.S. 2007. Physical activity and inactivity profiling: The next generation this article is part of a supplement entitled advancing physical activity measurement and guidelines in canada: A scientific review and evidence-based foundation for the future of Canadian physical activity guidelines co-published by applied physiology, nutrition, and metabolism and the canadian journal of public health, 32(S2E), pp.S195-S207.

Espie C. A., Watkins J., Duncan R., Sterrich M., McDonagh E., Espie A. & MCGarvie C. (2003) Perspectives on epilepsy in people with Intellectual Disabilities. Comparison of family carer, staff carer and clinician score profiles on the Glasgow epilepsy Outcome Scale. Seizure 12, 195–202.

Faggiano, P. D'Aloia, A. Gualeni, A. Lavatelli, A. and Giordano, A. 1997. Assessment of oxygen uptake during the 6-minute walking test in patients with Heart Failure: Preliminary experience with a portable device. *American Heart Journal,* 134(2), pp.203-206.

Falvo, M.J. and Earhart, G.M. 2009. Six-minute walk distance in persons with parkinson disease: A hierarchical regression model. *Archives of Physical Medicine and Rehabilitation,* 90(6), pp.1004-1008.

Fernhall, B. Millar, A.L. Pitetti, K.H. Hensen, T. and Vukovich, M.D. 2000. Cross validation of the 20-m shuttle run test for children and adolescents with Mental Retardation. *Adapted Physical Activity Quarterly,* 17(4), pp.402-412.

Fernhall, B. Tymeson, G.T. and Webster, G.E. 1988. Cardiovascular fitness of mentally retarded individuals. *Adapted Physical Activity Quarterly,*

Finlay, W.M.L and Lyons, E. 2001. Methodological issues in interviewing and using self-report questionnaires with people with Mental Retardation. *Psychological Assessment,* 13(3), pp.319-335.

Fisher, K. 2004. Health Disparities and Mental Retardation. *Journal of Nursing Scholarship,* 36(1), pp.48-53.

Freedson, P.S. Melanson, E. and Sirard, J. 1998. Calibration of the computer science and applications, inc. accelerometer. *Medicine and Science in Sports and Exercise,* 30(5), pp.777-781.

Frey, G.C. Buchanan, A.M. and Sandt, D.D.R. 2005. "I'd rather watch TV": An examination of physical activity in adults with Mental Retardation. *Journal Information,* 43(4),

Frey, G.C. Stanish, H.I. and Temple, V.A. 2008. Physical activity of youth with Intellectual Disability: Review and research agenda. *Adapted Physical Activity Quarterly,* 25(2), pp.95.

Fujiura, G.T. 2012. Self-reported health of people with Intellectual Disability. *Intellectual and Developmental Disabilities,* 50(4), pp.352-369.

Gerber, P.J. Batalo, C.G. and Achola, E.O. 2012. Dyslexia and learning disabilities in Canada and the UK: The impact of its disability employment laws. *Dyslexia,* 18(3), pp.166-173.

Giacobbi, J. Peter R. Stancil, M. Hardin, B. and Bryant, L. 2008. Physical activity and quality of life experienced by highly active individuals with physical disabilities. *Adapted Physical Activity Quarterly,* 25(3), pp.189-207.

Graham, A. and Reid, G. 2000. Physical fitness of adults with an intellectual disability: A 13-year follow-up study. *Research Quarterly for Exercise and Sport,* 71(2), pp.152-161.

Hannon, F. Fitzsimon, N. and Kelleher, C. 2006. Physical activity, health and quality of life among people with disabilities- an analysis of the SLÁN data. . *National Disability Authority.,*

Haskell, W. Lee, I. Pate, R. Powell, K. Blair, S. Franklin, B. Macera, C. Heath, G. Thompson, P. and Bauman, A. 2008. Physical activity and public health, updated recommendation for adults from the American College of Sports Medicine and the American Heart Association. *Circulation,* 116.

Hawkins, A. and Look, R. 2006. Levels of engagement and barriers to physical activity in a population of adults with learning disabilities. *British Journal of Learning Disabilities,* 34(4), pp.220-226.

Heller, T. Hsieh, K. and Rimmer, J. 2003. Barriers and supports for exercise participation among adults with down syndrome. *Journal of Gerontological Social Work,* 38(1-2), pp.161-178.

Hilgenkamp, T.I. van Wijck, R. and Evenhuis, H.M. 2012a. Feasibility and reliability of physical fitness tests in older adults with Intellectual Disability: A pilot study. *Journal of Intellectual and Developmental Disability,* 37(2), pp.158-162.

Hilgenkamp, T.I. van Wijck, R. and Evenhuis, H.M. 2012b. Low physical fitness levels in older adults with ID: Results of the HA-ID study. *Research in Developmental Disabilities,* 33(4), pp.1048-1058.

Hilgenkamp, T.I.M., van Wijck, R. and Evenhuis, H.M. 2013. Feasibility of eight physical fitness tests in 1,050 older adults with Intellectual Disability: Results of the healthy ageing with Intellectual Disabilities Study. *Intellectual and Developmental Disabilities,* 51(1), pp.33-47.

Hinckson, E.A. and Curtis, A. 2013. Measuring physical activity in children and youth living with Intellectual Disabilities: A Systematic Review. *Research in Developmental Disabilities,* 34(1), pp.72-86.

Howie, E.K., Barnes T.L., McDermott S., Mann J.R., Clarkson J. and Meriwether R.A. 2012. Availability of physical activity resources in the environment for adults with intellectual disabilities . *Disabil Health J.,* 5(1), pp.41-48.

Jans, M.P. Proper, K.I. and Hildebrandt, V.H. 2007. Sedentary behavior in dutch workers: Differences between occupations and business sectors. *American Journal of Preventive Medicine,* 33(6), pp.450-454.

Jones, E. Perry, J. Lowe, K. Felce, D. Toogood, S. Dunstan, F. Allen, D. and Pagler, J. 1999. Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: The impact of training staff in active support. *Journal of Intellectual Disability Research,* 43(3), pp.164-178.

Karinkanta, S. Heinonen, A. Sievänen, H. Uusi-Rasi, K. Fogelholm, M. and Kannus, P. 2009. Maintenance of exercise-induced benefits in physical functioning and bone among elderly women. *Osteoporosis International,* 20(4), pp.665-674.

Karlsson, A. and Opava, C.H. 2008. Cycling or walking? Comparing the six-minute walk with the cycle ergometer test in patients with Rheumatoid Arthritis. *Advances in Physiotherapy,* 10(4), pp.203-208.

Kelly, F. Kelly, C. and o'Donohoe, A. 2013. *National intellectual disability database committee- Annual report of the national intellectual disability database committee 2012*. An Bord Taighde Sláinte Grattan House 67–72 Lower Mount Street Dublin 2 Ireland: Health Research Board.

Klesges, R. Eck, L. Mellon, M. Fulliton, W. Somes, G. and Hanson, C. 1990. The accuracy of self-reports of physical activity. *Med Sci Sports Exerc.,* 22(5), pp.690-697.

Krahn, G. Hammond, L. Turner, A. 2006. A cascade of disparities: Health and health care access for people with Intellectual Disabilities. *Mental retardation and developmental disabilities research reviews,* 12pp.70-82.

Lee, I.M. 2003. Physical activity and cancer prevention-data from epidemiologic studies. *Medicine & Science in Sports & Exercise,* pp.1823-1827.

Lee, I.M. and Shiroma, E.J. 2014. Using accelerometers to measure physical activity in large-scale epidemiological studies: Issues and challenges. *British Journal of Sports Medicine,* 48(3), pp.197-201.

Leger, L.L. 1982. A maximal multistage 20-m shuttle run test to predict VO^2 max. *European Journal of Applied Physiology and Occupational Physiology,* 49(1), pp.1-12.

Macera, C. Hootman, J. and Sniezek, J. 2003. Major public health benefits of Physical Activity, Arthritis & Rheumatism (Arthritis Care & Research). *American College of Rheumatology,* 49(1), pp.122-128.

Mactavish, J.B. Mahon, M.J. and Lutfiyya, Z.M. 2000. “I can speak for myself”: Involving individuals with intellectual disabilities as research participants. *Mental Retardation,* 38(3), pp.216-227.

Mahy, J. Shields, N. Taylor, N.F. and Dodd, K.J. 2010. Identifying facilitators and barriers to physical activity for adults with Down Syndrome. *Journal of Intellectual Disability Research,* 54(9), pp.795-805.

Mathie, M.J. Coster, A.C. Lovell, N.H. and Celler, B.G. 2004. Accelerometry: Providing an integrated, practical method for long-term, ambulatory monitoring of human movement. *Physiological Measurement,* 25(2), pp.R1.

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

McCarron, M. McCallion, P. Carroll, R. Burke, E. Cleary, E. McCausland, D. McGlinchy, E. O'Donovan, M. Mulryan, N. and Shivers, C. 2014. Advancing years, different challenges: Wave 2 IDS-TILDA: Findings on the ageing of people with an intellectual disability: An intellectual disability supplement to the irish longitudinal study on ageing.

McArdle, W.D. Katch, F.I. and Katch, V.L. 2006. *Essentials of exercise physiology.* Lippincott Williams & Wilkins.

Messent, P. R.Cooke, C. B. and Long, J. 1999. Primary and secondary barriers to physically active healthy lifestyles for adults with learning disabilities. *Disability & Rehabilitation,* 21(9), pp.409-419.

Miller, R. and Brown, W. 2004. *Meeting Physical Activity Guidelines and Average Daily Steps in a Working Population.*

Moone, M.S. and Renzaglia, A. 1982. *1. Physical fitness and the mentally retarded: A critical review of the literature*. *Journal of Special Education,* 16(3), pp.269-287.

Moran, R. Drane, W. McDermott, S. Dasari, S. Scurry, J.B. and Platt, T. 2005. Obesity among people with and without mental retardation across adulthood. *Obesity Research,* 13(2), pp.342-349.

Mutrie, N. Campbell, A.M. Whyte, F. McConnachie, A. Emslie, C. Lee, L. Kearney, N. Walker, A. and Ritchie, D. 2007. Benefits of supervised group exercise programme for women being treated for early stage breast cancer:

Pragmatic randomised controlled trial. *BMJ (Clinical Research Ed.),* 334(7592), pp.517.

Myers, J. 2003. Exercise and cardiovascular health. *Circulation,* 107pp.2-5.

Nasuti, G. Stuart-Hill, L. and Temple, V.A. 2013. The six-minute walk test for adults with intellectual disability: A study of validity and reliability. *Journal of Intellectual and Developmental Disability,* 38(1), pp.31-38.

National Disability Authority 2005. *Promoting the Participation of People with Disabilities in Physical Activity and Sport in Ireland*

Nishiyama, S. Kuwahara, T. and Matsuda, I. 1986. Decreased bone density in severely handicapped children and adults, with reference to the influence of limited mobility and anticonvulsant medication. *European Journal of Pediatrics,* 144(5), pp.457-463.

Oja, P. Bull, F.C. Fogelholm, M. and Martin, B.W. 2010. Physical activity recommendations for health: What should europe do? *BMC Public Health,* 10pp.10-2458-10-10.

Onorati, P. Antonucci, R. Valli, G. Berton, E., De Marco, F., Serra, P. and Palange, P. 2003. Non-invasive evaluation of gas exchange during a shuttle walking test vs. a 6-min walking test to assess exercise tolerance in COPD patients. *European Journal of Applied Physiology,* 89(3-4), pp.331-336.

Oppewal, A. Hilgenkamp, T.I. van Wijck, R. and Evenhuis, H.M. 2013. Cardiorespiratory fitness in individuals with Intellectual Disabilities—A Review. *Research in Developmental Disabilities,* 34(10), pp.3301-3316.

Perry, J. and Felce, D. 2002. Subjective and objective quality of life assessment: Responsiveness, response bias, and resident: Proxy concordance. *Journal Information,* 40(6),

Peters, T.M. Moore, S.C. Xiang, Y.B. Yang, G., Shu, X.O. Ekelund, U. Ji, B. Tan, Y.T. Liu, D.K. and Schatzkin, A. 2010. Accelerometer-Measured Physical

Activity in Chinese adults. *American Journal of Preventive Medicine,* 38(6), pp.583-591.

Peterson, J.J. Janz, K.F. and Lowe, J.B. 2008. Physical activity among adults with intellectual disabilities living in community settings. *Preventive Medicine,* 47(1), pp.101-106.

Pett, M. Clark, L. Eldredge, A. Cardell, B. Jordan, K. Chambless, C. and Burley, J. 2013. Effecting healthy lifestyle changes in overweight and obese young adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities,* 118(3), pp.224-243.

Phillips, A.C and Holland, A.J. 2011. Assessment of objectively measured physical activity levels in individuals with intellectual disabilities with and without Down's Syndrome. *PLoS One,* 6(12), pp.e28618.

Pitetti, K.H. Beets, M.W. and Flaming, J. 2009. Accuracy of pedometer steps and time for youth with intellectual disabilities during dynamic movements. *Adapted Physical Activity Quarterly,* 26(4), pp.336-351.

Prasher, V.P. and Janicki, M.P. 2002. *Physical health of adults with intellectual disabilities.* Wiley Online Library.

Ries, J.D. Echternach, J.L. Nof, L. and Gagnon Blodgett, M. 2009. Test-retest reliability and minimal detectable change scores for the timed "up & go" test, the six-minute walk test, and gait speed in people with alzheimer disease. *Physical Therapy,* 89(6), pp.569-579.

Rimmer, J.H. Heller, T. Wang, E. and Valerio, I. 2004. Improvements in physical fitness in adults with down syndrome. *Journal Information,* 109(2),

Rintala, P. Dunn, J.M. McCubbin, J.A. and Quinn, C. 1992. Validity of a cardiorespiratory fitness test for men with mental retardation. *Medicine and Science in Sports and Exercise,* 24(8), pp.941-945.

Rintala, P. McCubbin, J.A. and Dunn, J.M. 1995. Familiarization process in cardiorespiratory fitness testing for persons with mental retardation. *Research in Sports Medicine: An International Journal,* 6(1), pp.15-27.

Rintala, P. McCubbin, J.A. Downs, S.B. and Fox, S.D. 1997. Cross validation of the 1-mile walking test for men with mental retardation. *Medicine and Science in Sports and Exercise,* 29(1), pp.133-137.

Rippe, J.M. Ward, A. Porcari, J.P. and Freedson, P.S. 1988. Walking for health and fitness. *Jama,* 259(18), pp.2720-2724.

Robertson, J. Emerson, E. Gregory, N. Hatton, C. Turner, S. Kessissoglou, S. and Hallam, A. 2000. Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities.*Research in Developmental Disabilities,* 21(6), pp.469-486.

Robertson, J. and Emerson, E. 2010. Participation in sports by people with intellectual disabilities in England: A Brief Report. *Journal of Applied Research in Intellectual Disabilities,* 23(6), pp.616-622.

Salzman, S.H. 2009. The 6-min walk test: Clinical and research role, technique, coding, and reimbursement. *CHEST Journal,* 135(5), pp.1345-1352.

Strohle, A. Physical activity, exercise, depression and anxiety disorders. Journal of neural transmission, 116(6) pp. 777-784.

Sirard, J.R. Trost, S.G. Pfeiffer, K.A. Dowda, M. and Pate, R.R. 2005. Calibration and evaluation of an objective measure of physical activity in preschool children. *Journal of Physical Activity and Health,* 2(3), pp.345.

Speakman, J. 1997. *Doubly labelled water: Theory and Practice.* Springer Science & Business Media.

Stalker, K. 1998. Some ethical and methodological issues in research with people with learning difficulties. *Disability and Society,* 13(1), pp.5-19.

Stanish, H.I. and Draheim, C.C. 2005. Assessment of walking activity using a pedometer and survey in adults with mental retardation. *Adapted Physical Activity Quarterly,* 22(2), pp.136-145.

Sturm, R. 2002. The effects of obesity, smoking, and drinking on medical problems and costs. *Health Affairs (Project Hope),* 21(2), pp.245-253.

Taggart, L. and Cousins, W. 2014. *Health promotion for people with intellectual and developmental disabilities.* McGraw-Hill Education (UK).

Tassé, M.J. Luckasson, R. and Nygren, M. 2013. AAIDD proposed recommendations for ICD–II and the condition previously known as mental retardation. *Intellectual & Developmental Disabilities,* 51(2), pp.127-131.

Temple, V.A. Anderson, C. and Walkley, J.W. 2000. Physical activity levels of individuals living in a group home. *Journal of Intellectual and Developmental Disability,* 25(4), pp.327-341.

Temple, V.A. and Walkley, J.W. 2003. Physical activity of adults with intellectual disability. *Journal of Intellectual and Developmental Disability,* 28(4), pp.342-353.

Temple, V.A. 2009. Factors associated with high levels of physical activity among adults with intellectual disability. *International Journal of Rehabilitation Research.Internationale Zeitschrift Fur Rehabilitationsforschung.Revue Internationale De Recherches De Readaptation,* 32(1), pp.89-92.

Temple, V.A. 2007. Barriers, enjoyment, and preference for physical activity among adults with intellectual disability. *International Journal of Rehabilitation Research.Internationale Zeitschrift Fur Rehabilitationsforschung.Revue Internationale De Recherches De Readaptation,* 30(4), pp.281-287.

Troiano, R.P. Berrigan, D. Dodd, K.W., Masse, L.C., Tilert, T. and McDowell, M. 2008. Physical activity in the United States measured by accelerometer. *Medicine and Science in Sports and Exercise,* 40(1), pp.181.

Troosters, T. Gosselink, R. and Decramer, M. 1999. Six minute walking distance in healthy elderly subjects. *European Respiratory Journal,* 14(2), pp.270-274.

Trost, S.G. Owen, N. Bauman, A.E. Sallis, J.F. and Brown, W. 2002. Correlates of adults' participation in physical activity: Review and update. *Medicine and Science in Sports and Exercise,* 34(12), pp.1996-2001.

Tucker, J.M. Welk, G.J. and Beyler, N.K. 2011. Physical activity in U.S. adults: Compliance with the physical activity guidelines for americans. *American Journal of Preventive Medicine,* 40(4), pp.454-461.

Tudor-Locke, C. and Bassett Jr, D.R. 2004. How many steps/day are enough? *Sports Medicine,* 34(1), pp.1-8.

Tudor-Locke, C. Craig, C.L. Aoyagi, Y. Bell, R.C. Croteau, K.A. De Bourdeaudhuij, I. Ewald, B. Gardner, A.W. Hatano, Y. and Lutes, L.D. 2011. How many steps/day are enough? for older adults and special populations. *Int J Behav Nutr Phys Act,* 8(1), pp.80.

UNESCO Chair 2014. *Transforming the lives of people with disabilities theri families and communities, through physical education, sport, recreation and fitness* [Online]. Available from:http://www.ittralee.ie/en/InformationAbout/Research/ResearchCentres/UNESCOChairinInclusivePhysicalEducationSportFitnessandRecreation/ [Accessed 01 July 2015].

U.S. Department of Health and Human Services [DHHS] 2008. *Physical activity guidelines advisory committee report.* Washington, DC: US Department of Health and Human Services.

Van de Mortel, Thea F. 2008. Faking it: Social desirability response bias in self-report research.

van Schrojenstein Lantman-de Valk H. M. J., Metsemakers J. F. M., Haveman M. J. & Crebolder H. F. J. M. (2000) Health problems in people with intellectual

disability in general practice: A Comparative Study. Family Practice 17, 405–407.

Vis, J.C. Thoonsen, H. Duffels, M.G. de Bruin-Bon, R.A., Huisman, S.A. van Dijk, A.P. Hoendermis, E.S. Berger, R.M. Bouma, B.J. and Mulder, B.J. 2009. Six-minute walk test in patients with down syndrome: Validity and reproducibility. *Archives of Physical Medicine and Rehabilitation,* 90(8), pp.1423-1427.

Walsh, P.N. 2008. Health indicators and intellectual disability. *Current Opinion in Psychiatry,* 21(5), pp.474-478.

Waninge, A. Evenhuis, I.J. van Wijck, R. and van der Schans, C.P. 2011. Feasibility and reliability of two different walking tests in people with severe intellectual and sensory disabilities. *Journal of Applied Research in Intellectual Disabilities,* 24(6), pp.518-527.

Warburton, D. Crystal, N. and Bredin, S. 2006. Prescribing exercise as preventive Therapy<*br* />. *Canadian Medical Association Journal,* 174(7), pp.961-974.

Warburton, D.E.R. Gledhill, N. and Quinney, A. 2001. Musculoskeletal fitness and health. *Canadian Journal of Applied Physiology,* 26(2), pp.217-237.

Ward, M. McGee, H. Morgan, K. Van Lente, E. Layte, R. Barry, M. Watson, D. Shelley, E. and Perry, I. (2009) SLÁN 2007: Survey of Lifestyle, Attitudes and Nutrition in Ireland. 'One Island – One Lifestyle?' Health and lifestyles in the Republic of Ireland and Northern Ireland: Comparing the population surveys. SLÁN 2007 and NIHSWS 2005, Department of Health and Children. Dublin: The Stationery Office.

Washburn, R.A. Zhu, W. McAuley, E. Frogley, M. and Figoni, S.F. 2002. The physical activity scale for individuals with physical disabilities: Development and evaluation. *Archives of Physical Medicine and Rehabilitation,* 83(2), pp.193-200.

Weiss RA, 2000. Six minute walk test in severe COPD: reliability and effect of walking course layout and length. Paper presented at ACCP Conference; San Francisco

Weiss, J. Diamond, T. Demark, J. and Lovald, B. 2003. Involvement in special olympics and its relations to self-concept and actual competency in participants with developmental disabilities. *Research in Developmental Disabilities,* 24(4), pp.281-305.

Wells, M. Turner, S. Martin, D. and Roy, A. 1997. Health gain through screening-coronary heart disease and stroke: Developing primary health care services for people with intellectual disability. *Journal of Intellectual and Developmental Disability,* 22(4), pp.251-263.

World Health Organization and UNAIDS 2007. *Prevention of cardiovascular disease.* World Health Organization.

World Health Organization *STEPwise approach to surveillance (STEPS)* [Online].Availablefrom: http://www.who.int/chp/steps/en/ 2014.

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

Appendices

Appendix A

Consent Forms

PRIMARY PARTICIPANT CONSENT FORM

Special Olympics Programmes Health Impact Evaluation

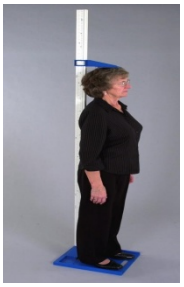
I give consent/assent to take part in the following areas of the research study

Please tick where agreed

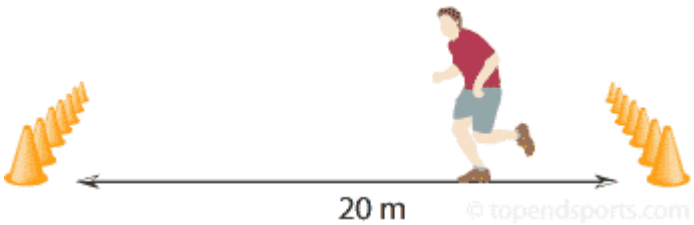
☐ Complete the health, diet and physical activity questionnaire



☐ Have weight, height and waist circumference measured in private


☐ Complete a short fitness test with trained researchers



A small number of you will also be asked to do the following 3 things:

☐ Keep a food and drink diary for four days

☐ Wear an activity monitor for one week

☐ Take part in a focus group discussion led by 2 trained researchers

Participants name _____

Participant's signature _____

Or Mark X _____ **(witnessed by 2 researchers)**

Name of service/club_____

Name of Participant_____

Name of family carer/member

_____

Home Address

_____

Contact number for family carer/member

_____

Signature of researcher 1

_____Date_____

Signature of researcher 2

_____Date_____ (if required)

Special Olympics Programmes Health Impact Evaluation

FAMILY CARER/ MEMBER CONSENT FORM

I give consent for my family member to take part in the following areas of the research study

- ☐ Complete health, diet and physical activity questionnaire
- ☐ Have weight, height and waist circumference measured in private
- ☐ Complete a short fitness test with trained researchers
- ☐ Wear an activity monitor for one week
- ☐ Keep a food and drink diary for four days
- ☐ Take part in a focus group discussion led by two trained researchers

Family carer/member's name

_____

Family carer/member's signature

_____

Special Olympics Programmes Health Impact Evaluation

FAMILY CARER/ MEMBER CONSENT FORM

I consent to take part in the following areas of the research study

☐ Complete health, diet and physical activity questionnaires

☐ Take part in a focus group discussion led by two trained researchers

Name of service/club

_____

Name of family member/carer_____

Home Address

_____

Contact number for family carer/member_____

Signature of family carer/member

_____ Date_____

Appendix B

Study Information Materials

Queen's University Belfast

DCU

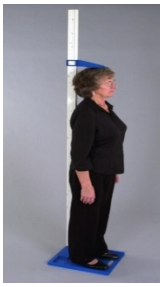
Special Olympics Ireland

You are invited to come join us in our study.

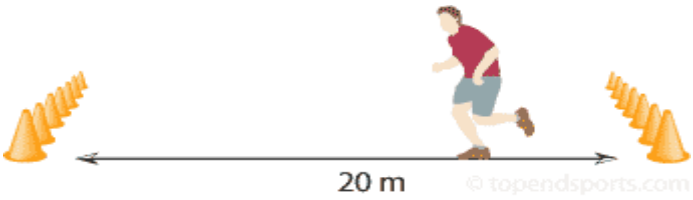
We would like you to do:

☐ **A health, diet and physical activity questionnaire**

☐ **Have weight, height, blood pressure and waist circumference measured in private**



☐ **A 6 minute walk test with a member of the team**



☐ **Keep a food and drink diary for four days**

A small number of you will also be asked to do the following 2 things:

☐ **Wear an activity monitor for one week**

☐ **Take part in a focus group discussion led by 2 trained researchers**

Frequently Asked Questions

You are being invited to take part in a study looking at the benefits of taking part in Special Olympics programmes, with a team of researchers from Dublin City University and Queens University Belfast. We are looking at whether those who take part in Special Olympics are healthier and happier than those who do not. We are also looking at the effect on family members of taking part in Special Olympics. If you want you can ask a family member or carer to read this information for you and help you understand what it is all about.

Why have I been chosen?

In this study we are inviting men and women over 16 years of age with an Intellectual Disability to take part.

Do I have to take part?

No you do not have to take part. It is up to you to decide whether or not you would like to take part. If you choose to take part **you can pull out at any time**.

What if I don't want to take part?

You won't miss out on anything if you do not take part.

What will happen to me if I take part?

There are 6 parts to the study.

1. We will ask you to fill in some questionnaires with the help of a family member. We will ask you questions about yourself such as if you are involved in sport such as Special Olympics, what foods you normally eat and how active you are.
2. We will then check your blood pressure and ask you to walk for 6 minutes (rests will be given if needed).
3. We will measure your weight, height and waist circumference.

4. We will ask you to fill in a diary for 4 days with all you have to eat and drink.
5. We will invite some people to take part in a group discussion on health, physical activity, nutrition and taking part in Special Olympics programmes.
6. A small number of participants will be asked to wear an activity monitor (accelerometer) around their waist for 1 week.

There are two other things that will happen.

1. A family member will be asked to fill in a questionnaire. We will ask questions about health and wellbeing, whether they volunteer with Special Olympics and the family income.
2. We will invite some family members/carers to take part in a group discussion on health, physical activity, nutrition and taking part in Special Olympics programmes.

Where can I get information about this study?

An information session will be held to tell you all about the study. You can come and hear more about the study to help you decide if you want to take part.

Will anyone help me if I have any questions?

The researchers will help and support you on the day. If you have any problems with the activity monitor or food diaries we will be around to help you.

What if I change my mind?

At any stage if you feel that you do not want to continue doing any of these things then you do not have to continue and you can stop.

Are there any risks of something bad happening to me if I take part?

We do not think anything bad will happen, however some small issues may arise such as:
You may not be fit enough for the 6 minute walk, you will be given a rest if needed
You may become upset or not like filling in the questionnaires, we can stop at any time
If you have to wear the activity monitor you may find it a little uncomfortable, we will do all we can to make sure you are wearing it properly
You may not feel comfortable having your weight, height and waist measured, we will ensure you have privacy for these
The research team will support and help you with any problems that do happen.

Are there any possible benefits of taking part?

You will get a copy of all the health measurements at the time and later in writing. By taking part you, your family and carers will be able to give important information about important issues that affect you to Special Olympics to help improve their programmes. They may get a better understanding of their role in the lives of people with an intellectual disability, what you want from them, how they can help to promote healthier lifestyles, how they can overcome barriers to people taking part and the cost benefits of their programmes.

What will be done with the answers I give?

All the answers you give will be private. You will be given a copy of your results. All the answers will be put together to make a report which may be published in a magazine, newspaper or book. Your name will not be written in the report.

If there is anything you don't understand feel free to ask any questions.

Thank you for reading this information, we look forward to meeting you.

If you would like to hear more about taking part in this project please contact Denise Walsh/ Edel Hoey (MSc Students) on 01-7005838/ 00353-1-7005838 or denise.walsh@dcu.ie edel.hoey4@mail.dcu.ie

Information SOPHIE Study

(Special Olympics Programmes Health Impact Evaluation) Study

We would like to welcome you to take part in a study looking at the impact of taking part in Special Olympics programmes, with a team of researchers from Dublin City University and Queens University Belfast. It will look at the health and wellness of people with intellectual disabilities who are involved and not involved in Special Olympics clubs.

People who agree to take part will be asked to tell us information about themselves such as their age, the service they go to, if they are involved in sport such as Special Olympics and what foods they normally eat. This information will be collected in a number of questionnaires which we and family or carers will help people to complete and a 4 day food and drink diary which you will take home. After this if they are happy to stay involved some measurements will be taken such as height, weight and blood pressure. For people who are able we will also ask them to do a 6 minute walk.

We are looking for members of a Special Olympics group, those not a member of a Special Olympics group or someone who has just joined a Special Olympics group. If you have just joined we will come back to do the same questions and measurements to see if there is any benefit to you in 9 months. If you are a member of a Special Olympics group (not a new member) or you are not taking part in any Special Olympics groups we will only need to come to get information from you once. We will then be comparing results of those who take part in Special Olympics programmes and those who do not take part.

We will be holding an information session on the day to answer any questions you may have.

If you would like to hear more about taking part in this project please contact Denise Walsh/ Edel Hoey (MSc Students) on 01-7005838/ 00353-1-7005838 or denise.walsh@dcu.ie

Appendix C

Primary Participant Questionnaire

Unique ID_____

If Special Olympics club please indicate if this is 1st time-point ☐[2] 2nd time- point ☐[3]

This questionnaire is to be completed by the study participants supported/helped by family members and/or carers.

Basic information about the Study Participant

Q1.Where were you recruited for this study?

Special Olympics Club ☐[1]

Or

Service: St. Michael's House ☐[2] Cope Foundation ☐[3] Western Care ☐[4]

Praxis Care ☐[5] Northern Health and Social Care Trust ☐[6]

Q2. Who is helping you to complete this questionnaire?
(This should be somebody who is very familiar with your normal daily routine)

Family member ☐[1] If yes was it Mother ☐[1] Father ☐[2] Sibling ☐[3] Other ☐[4]

Paid care staff ☐[2] If yes was it Your Keyworker ☐[1] Other staff member ☐[2]

If other please specify

_____

Q3. Do you attend a service: Yes☐[1] No☐[2] **If no, skip to question 7**

If yes, is it St. Michael's House☐[3] Cope Foundation ☐[4] Western Care ☐[5]

Other ☐[6] please state which one _____

Q3a. Are you a Day Attendee ☐[1] Resident ☐[2] **(Please tick both if apply)**

Q4. How many days a week do you get support from your service?

_____ days/week[1]

Q4a. For how many hours each day do on average you get support?

_____ hours/day[1]

Q5. How far do you live from your day service?

a) Less than 1km (1mile) ☐[1]
b) Between 2-5km (1-3miles) ☐[2]
c) Between 6-10km (4-6miles) ☐[3]
d) Between 11-15km (7-9miles) ☐[4]
e) Between 16-25km (10-16miles) ☐[5]
f) Greater than 25km (16miles) ☐[6]
g) Don't' know ☐[7]
h) Resident in service ☐[8]

Q6. How do you travel to your day service?

a) Walk ☐[1]
b) Public transport ☐[2]
c) Driven by family member ☐[3]
d) Transport provided by service ☐[4]
e) Other, please specify below ☐[5]
f) Resident in service ☐[6]

Q7. Do you take part in Special Olympics clubs?

Yes ☐[1] **If yes, continue to question 8**

No ☐[2]

Q7a. If no, which of the following applies to you?

No, but would like to ☐[1] **Continue to question 13**

No, and don't want to ☐[2] **Continue to question 13**

Used to ☐[3] **Continue to question 15**

Q8. If yes, how far do you live from your nearest Special Olympics club?

i) Less than 1km (1mile) ☐[1]
j) Between 2-5km (1-3miles) ☐[2]
k) Between 6-10km (4-6miles) ☐[3]
l) Between 11-15km (7-9miles) ☐[4]
m) Between 16-25km (10-16miles) ☐[5]
n) Greater than 25km (16miles) ☐[6]
o) Don't' know ☐[7]

Q9. How do you travel to your Special Olympics club?

a) Walk ☐[1]
b) Public transport ☐[2]
c) Driven by family member ☐[3]
d) Transport provided by service ☐[4]
e) Other, please specify below ☐[5]

Q10. Please list which club or clubs you attend below.

_____
_____

-

_____
_____

Q11. When did you first join a Special Olympics club?

m m / y y y y **Or if unknown please provide the year you first joined_____**

Q12. Do you take part in the Special Olympics Health Promotion Programme?

Yes ☐[1] No ☐[2] Don't Know ☐[3]

Q12a. If no, which of the following applies? No, but I would like to ☐[1]

No and I don't want to ☐[2] Never heard of it ☐[3]

Please skip to question 17

Q13. If you answered no to question 7 please choose why not from the list below:

a.	Not interested in sport	☐[1]
b.	No local club	☐[2]
c.	Difficulties with transport	☐[3]
d.	Cannot due to medical reasons	☐[4]
e.	Negative media publicity	☐[5]
f.	Was never asked/invited	☐[6]
g.	Never heard about it	☐[7]
h.	Tried but couldn't get in	☐[8]
i.	No space in local club	☐[9]
j.	Time does not suit	☐[10]
k.	Venue does not suit	☐[11]
l.	Don't have the family support I need to attend	☐[12]
m.	Local club does not offer my preferred sport	☐[13]
n.	Prevented joining due to my challenging behaviour	☐[14]
o.	Other reasons, please specify below	☐[15]

Q14. Do you know how far you live from your nearest Special Olympics club?

p)	Less than 1km (1mile)	☐[1]
q)	Between 2-5km (1-3miles)	☐[2]
r)	Between 6-10km (4-6miles)	☐[3]
s)	Between 11-15km (7-9miles)	☐[4]
t)	Between 16-25km (10-16miles)	☐[5]
u)	Greater than 25km (16miles)	☐[6]
v)	Don't' know	☐[7]

Please skip to question 17

Q15. . If you answered used to to question 7 please choose why not from the list below:

a.	No longer interested	☐[1]
b.	Local club closed	☐[2]
c.	Difficulties with transport	☐[3]
d.	Cannot due to medical reasons	☐[4]
e.	Negative media publicity	☐[5]
f.	No benefit of participation	☐[6]
g.	I didn't like/don't enjoy it	☐[7]
h.	My service provider no longer offers it	☐[9]

i. Time does not suit ☐10
j. Venue does not suit ☐11
k. Don't have the family support I need to attend ☐12
l. Local club does not offer my preferred sport ☐13
m. Had to leave due to my challenging behaviour ☐14
n. Other reasons, please specify below ☐15

Q16. How far do you live from your nearest Special Olympics club?

a) Less than 1km (1mile) ☐1
b) Between 2-5km (1-3miles) ☐2
c) Between 6-10km (4-6miles) ☐3
d) Between 11-15km (7-9miles) ☐4
e) Between 16-25km (10-16miles) ☐5
f) Greater than 25km (16miles) ☐6
g) Don't' know ☐7

Your General Health

Q17. Male ☐1 **Female** ☐2

Q18. What age are you? _____ years

Date of birth: ____ / ____ / _____

Q19. Is your daily activity limited by a long term illness, health problem or disability?

Yes ☐1 No ☐2

If you answered yes what is the long term illness, health problem or disability?

LIST _____

Q20. Would you describe your disability as mild ☐1 **moderate** ☐2 **severe** ☐3

Q20. Have you been diagnosed with any of the following?

Down's Syndrome ☐1 Cerebral Palsy ☐2
Autism ☐3 Non-specific Intellectual Disability ☐4
Fragile X ☐5 Other_____ ☐6

Q21. Which of the following best describes your level of mobility?

Fully mobile ☐1
In need of mobility aids ☐2
Wheelchair user ☐3

Q22. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care (that is looking after yourself), work or recreation?

Number of days _____ None ☐0

Q23. Have you had any of the following in the last 12 months? If yes, was this condition diagnosed by a doctor?
Please tick the relevant boxes in the table below.

Condition	Have you had any of the following in the past 12 months?		If yes, was this diagnosed by a doctor?	
	Yes[1]	No[2]	Yes[3]	No[4]
Asthma [a]				
Chronic bronchitis, chronic obstructive lung (pulmonary) disease, emphysema [b]				
Heart attack [c]				
Angina [d]				
Stroke [e]				
Rheumatoid arthritis (inflammation of the joints) [f]				
Osteoarthritis (arthrosis, joint degeneration)/ osteoporosis/ osteopenia [g]				
Lower back pain/ other chronic back condition [h]				
Diabetes [i]				
High blood pressure [j]				
High cholesterol [k]				
Cancer (malignant tumour, also including leukaemia & lymphoma) [l]				
Urinary incontinence, problems in controlling the bladder [m]				
Anxiety [n]				
Depression [o]				
Schizophrenia [p]				
Epilepsy [q]				
Other, please specify [r] _____				

Q24. In the last 12 months, have you been screened or tested for any of the following?
Please tick the relevant boxes in the table below.

Condition	Have you been screened in the past 12 months?		If yes, where was this done?				
	Yes[1]	No[2]	GP/ Family Doctor[3]	Health Clinic[4]	Hospital[5]	Workplace[6]	Other[7]
Diabetes [a]							
Blood pressure [b]							
Cholesterol [c]							
(Women) Breast cancer – mammogram [d]							
(Women) Cervical cancer-smear [e]							
(Men) Prostate cancer [f]							
(Men)Testicular cancer [g]							
Colon cancer or Bowel cancer [h]							
Osteoporosis/ DEXA scan [i]							

Q25. In the table below please indicate the number of contacts you have had with the following health services practitioners over the past 30 days. Please indicate the average number of hours per visit and tick whether it was in a clinic/ outpatients or at home? Please also indicate the total number of visits over the past 12 months.

Type of care	Number of visits during last 30 days[1]	Average number of minutes per visit[2]	Clinic/ outpatients[3] √	Home visit[4] √	Number of visits during the past 12 months[5]	Total (office use only)
General Practitioner (GP)[a]						
Other Doctor/Consultant (e.g. orthopedic surgeon)[b] Please specify						
Physiotherapist[c]						
Occupational Therapist[d]						
Social Worker[e]						
Psychologist[f]						
Dietitian[g]						
Speech & Language Therapist[h]						
Nursing Staff- District/Public Health/Community Nurse[i]						
Home help/Healthcare assistant/ Home carer[j]						
Other[k] (e.g. chiropodist) Please specify						

Q26. Please list in the table below any medications prescribed by a doctor that you take regularly.

Name of Medication	Date Started	Dose*	Times per Day

Q27. When was the last time you visited a dentist, dental hygienist or orthodontist for your own benefit?

In the last 4 weeks	Between 1 and 12 months ago	1-2 years ago	More than 2 years ago	Never
☐[1]	☐[2]	☐[3]	☐[4]	☐[5]

Q28. Which best describes the teeth you have?

I have all my own natural teeth – none missing ☐[1]
I have my own teeth, no dentures – but some missing ☐[2]
I have dentures as well as some of my own teeth ☐[3]
I have full dentures ☐[4]
I have no teeth or dentures ☐[5]

Q29. How many times do you brush your teeth each day?

Twice a day or more often	Once a day	Less than once a day
☐[1]	☐[2]	☐[3]

Q30. During the last 12 months, have you had any day case procedures (not requiring an overnight stay)?

Yes ☐[1] No ☐[2]

If you have not have you had any day case procedures in the last 12 months please continue to question 32.

Q31. For each day case procedure, please provide the reason for the procedure and the length of stay in the box below for the past 30 days and 12 months.

Day Procedure number	Reason for day procedure in the past 30 days[a]	Length of stay in hours[b]
I		
2		
3		
	Total (office use only)	
Day Procedure number	**Reason for day procedure in the past 12 months[a]**	**Length of stay in hours[b]**
4		
5		
6		
7		
8		
Any other procedures[9]		
	Total (office use only)	

Q32. During the last 12 months, did you receive care in a hospital Accident and Emergency department (without a hospital admission)?

Yes ☐[1] No ☐[2]

If you have not received care in a hospital Accident and Emergency department (without a hospital admission) in the last 12 months please continue to question 34.

Q33. If yes, for each time you received care in a hospital Accident and Emergency department (without a hospital admission) please provide the reason for receiving care and the length of stay in the box below for the past 30 days and 12 months.

A and E admission	Major diagnosis / reason for needing care in the past 30 days[a]	Length of stay in hours[b]
1		
2		
3		
4		
5		
Any other admissions[6]		
	Total (office use only)	

A and E admission	Major diagnosis / reason for needing care in the past 12 months[a]	Length of stay in hours[b]
7		
8		
9		
10		
11		
12		
13		
Any other admissions[14]		
	Total (office use only)	

Q34. During the last 12 months, were you admitted to a hospital (for more than 24 hours)?

Yes ☐[1] No ☐[2]

If you have not been admitted to a hospital (for more than 24 hours) in the last 12 months please continue to question 36.

Q35. For each hospitalisation (during the last 30 days and 12 months), please provide the diagnosis or reason for hospitalisation and the length of stay in the box below.

Hospitalisation number	Major diagnosis / reason for hospitalisation in the past 30 days[a]	Length of stay in days (counting the no. overnight stays)[b]
1		
2		
3		
4		
Any other admissions[5]		
	Total (office use only)	
Hospitalisation number	**Major diagnosis / reason for hospitalisation in the past 12 months[a]**	**Length of stay in days (counting the no. overnight stays)[b]**
6		
7		
8		
9		
10		
11		
12		
Any other admissions[13]		
	Total (office use only)	

Q36. The next set of questions is about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks …	All of the time[1]	Most of the time[2]	A good bit of the time[3]	Some of the time[4]	A little of the time[5]	None of the time[6]
Did you feel full of life? [a]						
Did you have a lot of energy? [b]						
Did you feel tired? [c]						
Did you feel worn out? [d]						

Q37. Have you often felt lonely in the last 4 weeks? Yes ☐[1] No ☐[2]

Your Physical Activity levels

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. This is any activity you do at work, in your care centre or in your Special Olympics club.

Q38. VIGOUROUS ACTIVITY

This is when you are working very hard and your heart beats fast.

Q38a. First can I ask you to think about activity during a ***NORMAL WE***

Basketball
_____ times per wk

Digging[2]
_____times per wk

Heavy lifting[3]
_____times per wk

Hard long distance cycling[4]
_____ times per wk

Please circle or list the activities that you do and note the number of times you normally do

Running[5]
_____ times per wk

Soccer[6]
_____times per wk

Hard swimming[7]
_____times per wk

Other_____ Times_____

_____ _____

_____ _____

I am now going to ask you about the time you spent doing vigorous physical activities _____ ***IN THE LAST 7 DAYS (for at least 10 minutes at a time).***

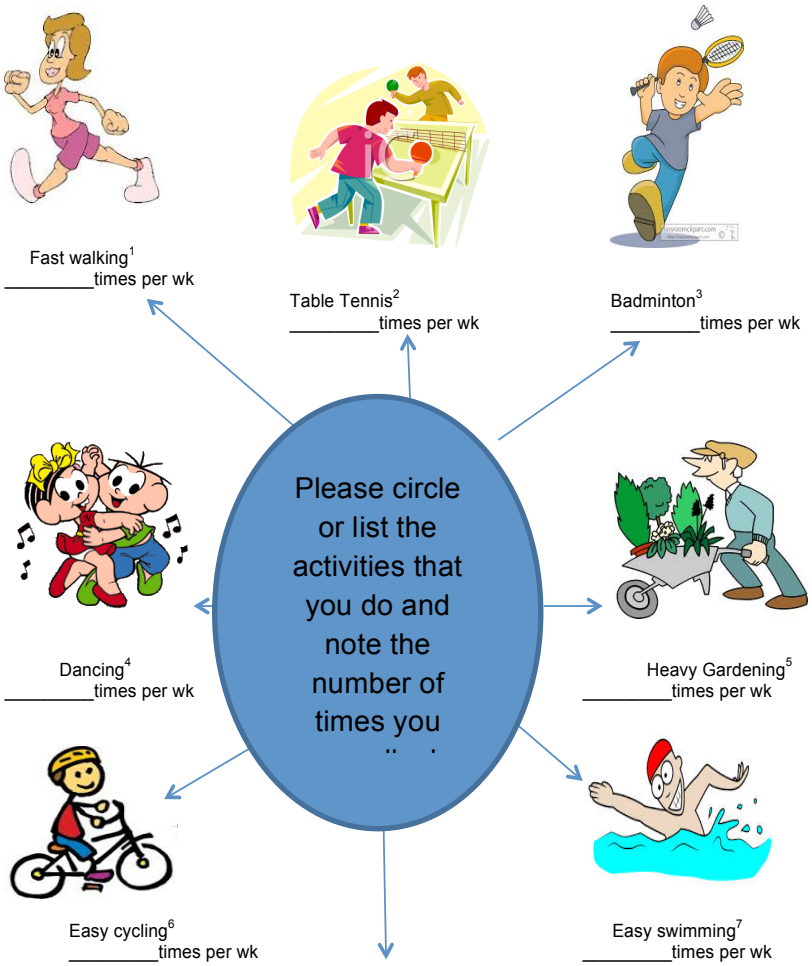
Q3
8b. During THE LAST 7 DAYS, on how many days did you do vigorous physical activity?

_____days per week **None ☐0** **If no, skip to question 39**

Q38c. How much time did you usually spend doing vigorous physical activities on one of those days?
_____/_____ hours and minutes per day Not sure/don't know
☐0

Q39. MODERATE ACTIVITY -
This is exercise that is not very hard, but it is not easy either.

Q39a. Can I ask you to think about moderate activity during a ***NORMALWEEK?*** **(7 days)**



Q39b. During <u>THE LAST 7 DAYS</u>, on how many days did you do <u>moderate physical activity</u>?

_____days per week **None ☐0** **If no, skip to question 40**

Q39c. How much time did you usually spend doing <u>moderate physical a</u>

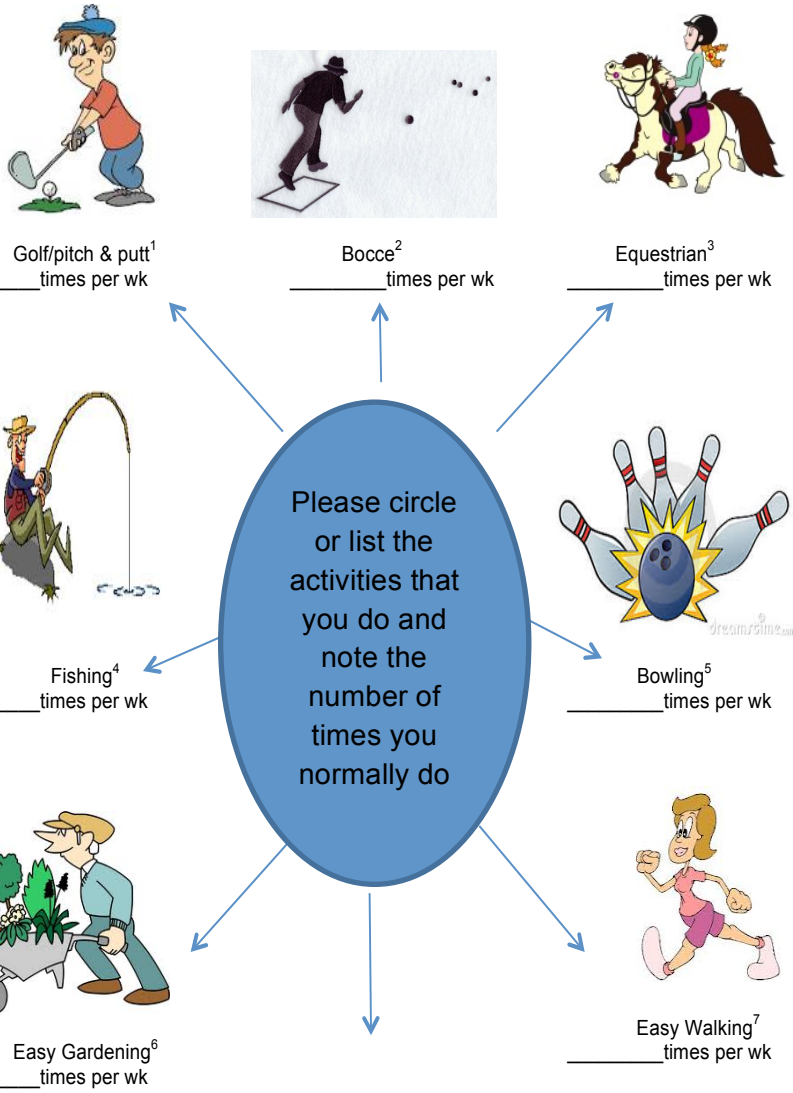
I am now going to ask you about the time you spent doing moderate physical activities ***<u>IN THE LAST 7 DAYS</u> (for at least 10 minutes at a time)***.

<u>ties</u> on one of those days?

_____/_____ hours and minutes per day Not sure/don't know ☐0

MILD ACTIVITY
This is activity that is easy.

Q40a. Can I ask you to think about mild activity during a



I am now going to ask you about the time you spent doing mild physical activities ***IN THE LAST 7 DAYS (for at least 10 minutes at a time).***

Q40b. During THE LAST 7 DAYS, on how many days did you do mild physical activity?

_____days per week **None ☐0** **If no, skip to question 41**

Q40c. How much time did you usually spend doing mild physical activities on one of those days?

_____/_____ hours and minutes per day Not sure/don't know ☐0

WALKING:

Q41. How many days, if any, in a *NORMAL WEEK* do you walk for more than 30 minutes or more?

_____days

Q42. Which of the following best describes your normal walking pace?

A slow pace A steady average pace A fairly brisk pace A fast pace- at least 4kmph

Q43. During THE LAST 7 DAYS, on how many days did you walk at a brisk/fast pace for at least 10 minutes at a time?

_____ days per week None ☐0 **If no, skip to question 45**

Q44. How much time did you usually spend walking on one of those days?

_____/_____ hours and minutes per day Not sure/don't know ☐0

Q45. If you are not as physically active as you would like to be, what would you say is the main reason why you are not (more) physically active at this time?

Not interested	☐1
Interested but not willing to spend the time	☐2
No time to do it	☐3
No facilities/places to exercise/be active	☐4
Injury/disability/medical condition	☐5
I feel I do enough physical activity	☐6
Other, specify _____	☐7

If you do not take part in Special Olympics clubs please skip to question 47.

Q46. Please tick which of the following sports you take part in with your Special Olympics club. How many hours per week do you do each sport?

Swimming[1] ☐ _____hours
Alpine Skiing[2] ☐ _____hours
Aquatics [3] ☐ _____ hours
Athletics[4] ☐ _____ hours
Badminton[5] ☐ _____ hours
Badminton[6] ☐ _____ hours
Basketball[7] ☐ _____ hours
Bocce[8] ☐ _____ hours
Bowling[9] ☐ _____ hours
Equestrian [10] ☐ _____ hours
Floorball [11] ☐ _____ hours
Football [12] ☐ _____ hours
Golf [13] ☐ _____ hours
Gymnastics[14] ☐ _____ hours
Kayaking [15] ☐ _____ hours
Pitch & Putt[16] ☐ _____ hours
Table Tennis[17] ☐ _____ hours
Motor Activity
Training Program[18] ☐ _____ hours
Others [19] ☐ _____ hours

Total (office use only) _____
hours

Your Diet & Nutrition Status

Q47. Given your age and height, would you say that you are?

About the right weight ☐[1] Too heavy ☐[2] Too light ☐[3] Not sure ☐[4]

Q48. Are you actively trying to manage your weight?

Yes ☐[1] No ☐[2] **If no, skip to question 51**

Q49. If yes, is it to lose, gain or maintain weight?

Lose weight ☐[1] Maintain weight ☐[2] Gain weight ☐[3]

Q50. Are you using any of the following to lose/maintain weight?

	Yes	No	
Eating fewer calories[a]	☐ 1	☐ 2	
Physical activity[b]		☐ 1	☐ 2
Special diet[c]	☐ 1	☐ 2	Please state what this is

_____

Q51. In the past 12 months has a doctor, nurse or other health professional advised you to lose, maintain or gain weight?

Yes, lose weight ☐ 1 | Yes, maintain current weight ☐ 2 | Yes, gain weight ☐ 3 | No ☐ 4

Q52. How often do you eat fried food?

Daily ☐ 1 | 4-6 times a week ☐ 2 | 1-3 times a week ☐ 3 | Less than once a week ☐ 4

Q53. What type of milk do you use most often?

None ☐ 1 **Skip to question 55**

Whole milk/Full fat ☐ 2

Low fat ☐ 3

Skimmed ☐ 4

Super/fortified ☐ 5

Soya ☐ 6

Other, please specify_____ ☐ 7

Q54. How much milk do you drink each day?

None ☐ 1 | 250ml (half pint) ☐ 2 | 568 ml (one pint) ☐ 3 | One litre ☐ 4 | More than 1 litre ☐ 5

Q55. How often do you add salt to food while cooking?

Always ☐ 1 | Usually ☐ 2 | Sometimes ☐ 3 | Rarely ☐ 4 | Never ☐ 5

Q56. How often do you add salt to food while at the table?

Always ☐ 1 | Usually ☐ 2 | Sometimes ☐ 3 | Rarely ☐ 4 | Never ☐ 5

Q57. Do you make your own food choices?

Always ☐ 1 | Usually ☐ 2 | Sometimes ☐ 3 | Rarely ☐ 4 | Never ☐ 5

Q58. When you don't make your own food choices, who makes your food choices for you?

Family member ☐ 1 | Paid care worker ☐ 2 | Friend ☐ 3 | Neighbour ☐ 4

Other…….. ☐ 5 | Not applicable ☐ 6

Q59. Who usually prepares your meals?

Yourself- without support ☐ 1

Yourself- with support from family/friend/care staff ☐ 2

Family member ☐[3] Paid care worker ☐[4] Friend ☐[5] Neighbour ☐[6]
Other……..☐[7]

Q60. Who usually cooks your meals?
Yourself- without support ☐[1] Yourself- with support from family/friend/care staff ☐[2]

Family member ☐[3] Paid care worker ☐[4] Friend ☐[5] Neighbour ☐[6]
Other……..☐[7]

Q61. How would you describe your cooking skills?
Poor ☐[1] Fair ☐ Average☐[3] Good ☐[4] Very Good ☐[5]

Q62. Who usually does your food shopping?
Yourself- without support ☐[1] Yourself- with support from family/friend/care staff ☐[2]

Family member ☐[3] Paid care worker ☐[4] Friend ☐[5] Neighbour ☐[6]
Other……..☐[7]

Q63. Do you plan what foods are bought for you?
Always ☐[1] Usually ☐[2] Sometimes ☐[3] Rarely ☐[4]
Never ☐[5]

Q64. Did you eat snacks between your meals yesterday?
Yes ☐[1] No ☐[2] **If no, skip to question 66**

Q64a. If yes, how many snacks did you have? _____

Q65. If yes, what types of snacks did you eat? (Please tick all that apply)

Biscuits/Cake	☐[1]	Scone	☐[2]
Crisps/Popcorn/Pretzels	☐[3]	Chocolate	☐[4]
Fruit	☐[5]	Dried fruit	☐[6]
Nuts	☐[7]	Yoghurt	☐[8]
Vegetables	☐[9]	Sweets	☐[10]
Other_____		☐[11]	

Q66. Who normally buys your snacks?
Yourself- without support ☐[1] Yourself- with support from family/friend/care staff ☐[2]

Family member ☐[3] Paid care worker ☐[4] Friend ☐[5] Neighbour ☐[6]
Other……..……..☐[7]

Q67. How often in a typical week do you drink fizzy drinks? (e.g. Coca cola, Fanta, Pepsi)

Daily ☐[1] 4-6 times a week ☐[2] 1-3 times a week ☐[3] Less than once a week ☐[4] Never ☐[5]

Q68. Do you regularly take any nutritional supplements?
Yes ☐[1] **No** ☐[2] **If no, skip to question 69**

Q68a. If yes, please tick all that apply below:

Multi vitamin supplements	☐ 1
Multi mineral supplements	☐ 2
Protein supplements (including shakes)	☐ 3
Weight loss aids	☐ 4
Oral nutritional supplements (e.g. Complan/Fortisip)	☐ 5
Other please specify_____	☐ 6

The following 2 questions are about the meals you had yesterday.

Q69. Where did you eat your breakfast, light meal and main/largest meal yesterday?

(Please tick all that apply)

	Break-fast[1]	**Light meal (e.g. light lunch, supper, tea)[2]**	**Main/ Largest Meal (e.g. dinner or heavy lunch)[3]**	**Snacks (e.g. sweets, chocolate, crisps, fruit, yoghurt)[4]**
Didn't have a…[a]				
At home [b]				
While travelling, taken from home [c]				
While travelling, take away [d]				
At work/school/college/day services packed at home [e]				
At work/school/college/day services take away [f]				
At a work/school/college/day services canteen [g]				
At a coffee shop/café [h]				
At a restaurant [i]				
Take away from a deli [j]				
Take away from a fast food restaurant [k]				
Somewhere else, (please specify) [l]				

Q70. What did you eat for your breakfast, light meal, and main meal yesterday?

(Please tick all that apply for each meal)

	Break-fast[1]	Light meal (e.g. light lunch, supper, tea)[2]	Large Meal (e.g. Dinner or heavy lunch)[3]
Didn't have a…[a]			
BREAKFAST FOODS			
Bread/toast/roll/bap/pitta bread (not as a sandwich)[b]			
High fibre breakfast cereal (including porridge)[c]			
Other breakfast cereal (including cereal bars)[d]			
Fruit[e]			
Cooked breakfast (including full Irish; eggs-boiled, fried, poached, scrambled)[f]			
Filled breakfast roll[g]			
Yoghurt[h]			
Croissant/Pastry/Scone[i]			
LUNCH/DINNER FOODS			
Meat/Fish/Vegetarian sandwich/bap/wrap/pitta[j]			
Soup[k]			
Pizza[l]			
Green salad/vegetables[m]			
Coleslaw/potato salad/egg salad[n]			
Cheese[o]			
Pasta/Rice[p]			
Potato-boiled/mashed/roast[q]			
Chips/wedges[r]			
Red meat/Chicken Fish[s]			
Other vegetables (e.g. carrots, cauliflower, corn)[t]			
Fast food take away (e.g. burger meal)[u]			
Sauce: Tomato/curry/vegetable based[v]			
Sauce: creamy[w]			
Other[x]			

Smoking Status

Q71. How many cigarettes do you smoke per day?

None	☐ 1	**If none, skip to question 73**
10 or less	☐ 2	
11-20	☐ 3	
21-30	☐ 4	
31 or more	☐ 5	

Q72. If you smoke are you currently?

Trying to quit	☐ 1
Actively planning to quit	☐ 2
Thinking about quitting but not planning to	☐ 3
Not thinking about quitting	☐ 4

Q73. Has being involved in Special Olympics made you quit or try to quit smoking?

Yes ☐ 1 No ☐ 2 Not Applicable ☐ 3

If yes, please state why

_____

Alcohol Intake

Q74. How often do you have a drink containing alcohol?

Never	☐ 1
Monthly or less	☐ 2
2-4 times a month	☐ 3
2-3 times a week	☐ 4
4 or more times a week	☐ 5

Q75. Has being involved in Special Olympics made you stop or reduce the amount of alcohol you drink?

Yes ☐ 1 No ☐ 2 Not Applicable ☐ 3

If yes, please state why

_____

Your Family, Social Networks & Neighbours

Q76. Do you regularly join in the activities of any of the following types of organisation?

(Please do not include Special Olympics Club involvement here)
(Please tick all that apply)

	Yes[1]	No[2]
Sports clubs (Parish, GAA, Golf, Other), gym, exercise classes [a]		
Political parties, trade unions, environmental groups [b]		
Parent-teacher associations, tenants groups, residents groups, neighbourhood watch, youth groups, other community action groups [c]		
Church or other religious/parish groups, charitable or voluntary organisations (e.g. collecting for charity, helping the sick, elderly) [d]		
Evening classes, arts or music groups, education activities [e]		
Social clubs (e.g. mother & toddler group, rotary club, women's groups, elderly group) [f]		
Theatre, drama groups, gigs/concert, pub [g]		
Other, please specify:_____ [h]		

Q77. How many people are so close to you that you can count on them if you have serious personal problems?

None ☐[1] 1 or 2 ☐[2] 3 to 5 ☐[3]
More than 5 ☐[4]

Q78. How much interest do people show in what you are doing?

A lot ☐[1] Some ☐[2] Uncertain ☐[3] Little ☐[4]
No concern ☐[5]

Your General Household Information

The information being collected in the next section is of a personal nature. Some people may find the questions sensitive. Please be assured that all answers will be treated in the strictest confidence and will not be shared or divulged to any persons outside the study team.

Q79. What is the highest level of education you have completed to date?

- Special education school ☐ 1
- None/ primary not complete ☐ 2
- Primary or equivalent ☐ 3
- Intermediate/Junior/ Group Certificate/GCSE or equivalent ☐ 4
- Leaving Certificate/A Levels or equivalent ☐ 5
- FETAC levels 1-5 ☐ 6
- Diploma/ Certificate ☐ 7
- Primary degree ☐ 8
- Postgraduate/ Higher degree ☐ 9

Q80. What is your <u>current</u> marital status?

Single (never married)	☐ 1	Separated	☐ 4
Cohabiting	☐ 2	Divorced	☐ 5
Married	☐ 3	Widowed	☐ 6

Q81. How many individuals live in your household in each of the following age categories?

- Adults (18-65) _____
- Adults (65+) _____
- Children (14-17) _____
- Children (5-13) _____
- Children (<5) _____
- Total _____

Q82. How many individuals in your household are currently working?

_____

Q83. WHICH of these descriptions BEST describes your usual situation in regard to work? (Please tick one only)

- Employee (incl. apprenticeship or Community Employment) ☐ 1
- Self-employed outside farming ☐ 2
- Farmer ☐ 3
- Student full-time ☐ 4
- On State training scheme (FÁS, Failte Ireland etc.) ☐ 5
- Unemployed, actively looking for a job ☐ 6
- Long-term sickness or disability ☐ 7
- Home duties / looking after the home or family ☐ 8
- Retired ☐ 9
- Other (specify) _____ ☐ 10

Q84. Please indicate which of the below that best describes where you live.

- Living at home ☐ 1
- 5-day community group home ☐ 2
- 7-day (48-week) community group home ☐ 3
- 7-day (52-week) community group home ☐ 4
- 5-day residential centre ☐ 5
- 7-day (48-week) residential centre ☐ 6
- 7-day (52-week) residential centre ☐ 7
- Nursing home ☐ 8
- Mental health community residence ☐ 9
- Psychiatric hospital ☐ 10
- Intensive placement (challenging behaviour) ☐ 11
- Intensive placement (profound or multiple disability) ☐ 12
- Other/unspecified intellectual disability service ☐ 13
- Designated residential support placement ☐ 14
- Other, Please Specify_____ ☐ 15

Q84a. If ticked option 'Living at home' is it

Owned with mortgage ☐ 1 Rented from Local Authority ☐ 2

Rented privately ☐ 3 Owned outright ☐ 4

Other ☐ 5

Please specify other

_____

Q85. Who do you live with?

- Alone ☐ 1
- Spouse/Partner ☐ 2
- Parent(s) ☐ 3
- Sibling ☐ 4
- Other individuals with an intellectual disability ☐ 5
- Care Staff ☐ 6
- Other, Please specify: _____ ☐ 7

Q86a. ROI Residents Only. Please tick any of the following you receive due to your disability?

- Disability Allowance ☐ 1
- Household Benefits Package ☐ 2
- Fuel Allowance ☐ 3
- Free Travel ☐ 4
- Respite Care Grant ☐ 5
- Other, Please Specify_____ ☐ 6

Q86b. NI Residents Only. Please tick any of the following you receive due to your disability?

- Disability Living Allowance ☐ 1
- Personal Independence Payment ☐ 2
- Working Tax Credit ☐ 3
- Employment and Support Allowance ☐ 4
- Incapacity Benefit ☐ 5

Severe Disablement Allowance ☐[6]

Respite Care Grant ☐[7]

Other, Please Specify_____ ☐[8]

Q87. Do you have the use of a car (including vans, minibuses, etc.)?

Yes ☐[1] No ☐[2]

Q88. Do you regularly use a computer, tablet or smart phone?

Yes ☐[1] No ☐[2]

Q89. Do you regularly use the internet?

Yes ☐[1] No ☐[2]

Q90. How frequently do you use the Internet to seek health information such as injury, physical activity, nutrition or performance in sport?

Daily ☐[1] Weekly ☐[2] Monthly ☐[3] Sometimes ☐[4]
Never ☐[5]

Q91. ROI Only. Are you covered by a medical card?

Yes – full medical card ☐[1] Yes – GP only medical card ☐[2]
No ☐[3]

Q92. Do you have private health insurance that covers the cost of private medical treatment (e.g. VHI, BUPA, VIVAS)?

Yes ☐[1] No ☐[2]

Q93. Would you describe the place where your household is situated as being…..?

In open country ☐[1] In a city (other than Dublin) ☐[4]
In a village ☐[2] In Dublin/Belfast City ☐[5]
In a town (1,500+) ☐[3]

Q94. In what country were you born?

Republic of Ireland ☐[1]
Northern Ireland ☐[2]
Other UK ☐[3]
Other, specify_____ ☐[4]

Q95. What is your ethnic or cultural background?

(a) White
Irish ☐[1] Irish Traveller ☐[2] British ☐[3] Any other white background ☐[4]

(b) Black or Black Irish
African ☐[5] Any other black background ☐[6]

(c) Asian or Asian Irish

Chinese ☐[7] Any other Asian background ☐[8]

(d) Other including mixed background ☐[9]

Insert own description

_____

Q96. What is your religion?

a) Roman Catholic ☐[1]
b) Presbyterian Church in Ireland ☐[2]
c) Church of Ireland ☐[3]
d) Methodist Church in Ireland ☐[4]
e) Other Christian ☐[5]
f) Islam ☐[6]
g) Jewish ☐[7]
h) Other_____ ☐[8]
i) No religion ☐[9]

Thank you for taking the time to complete this questionnaire.

NB** RESEARCHER PLEASE COMPLETE THE NEXT PAGE**

To be completed by research team

Q97. How long did the interview take ... less than 30 mins ☐1
30-60 mins ☐2
.. 60-90 mins ☐3
90-120 mins ☐4
over 120 mins ☐5

Q98. How much support did the study participant require to complete this questionnaire?

None- completed without support ☐1
Minimal support provided by family member/carer/researcher ☐2
Significant support provided by family member/carer/researcher ☐3
All questions answered by family member/carer ☐4

Q99. Researcher's comments on the interview

_____
_____
_____
_____
_____
_____

Interviewer Check list **Completed:**

Q100. Self EQ-5D-3L Yes ☐1 No – refused ☐2 No – unable ☐3

Q101. Carer's EQ-5D-3L on their behalf Yes ☐1 No – refused ☐2 No – unable ☐3

Q102. Height/Ulna Length Yes ☐1 No – refused ☐2 No – unable ☐3

Q103. Weight/Mid Upper Arm Circ. Yes ☐1 No – refused ☐2 No – unable ☐3

Q104. Waist Circumference Yes ☐1 No – refused ☐2 No – unable ☐3

Q105. Blood Pressure Measurements Yes ☐1 No – refused ☐2 No – unable ☐3

Q106. Resting Heart Rate Yes ☐1 No – refused ☐2 No – unable ☐3

Q107. Post PA Test Heart Rate Yes ☐1 No – refused ☐2 No – unable ☐3

Q108. 6 Minute Walk Yes ☐1 No – refused ☐2 No – unable ☐3

Q109. Primary Participant Questionnaire Yes ☐$_1$ No – refused ☐$_2$
No – unable ☐$_3$

Q110. Food diary Yes ☐$_1$ No – refused ☐$_2$ No – unable ☐$_3$

Q111. Accelerometer Yes ☐$_1$ No – refused ☐$_2$ No – unable ☐$_3$
Not required ☐$_4$

Date survey pack administered: _____ / _____ / _____

Date survey pack returned: _____ / _____ / _____

Completeness checked by researcher
_____ (signature)

Appendix D

Six Minute Walk Test Instructions

Pre-test: rest for 10 minutes. Measure heart rate, blood pressure

Lead Researcher:

- On the instructions to begin, start walking around the course as fast as you can.
- Do not run.
- If you feel tired, you can stop and rest on the chair provided.
- At the end of 6 minutes when you hear 'Stop' called out, stop exactly where you are.

- After the first minute, tell the patient the following (in even tones): "You are doing well. You have 5 minutes to go."
- When the timer shows 4 minutes remaining, tell the patient the following: "Keep up the good work. You have 4 minutes to go."
- When the timer shows 3 minutes remaining, tell the patient the following: "You are doing well. You are halfway done."
- When the timer shows 2 minutes remaining, tell the patient the following: "Keep up the good work. You have only 2 minutes left."
- When the timer shows only 1 minute remaining, tell the patients: "You are doing well. You have only 1 minute to go."

During the test, the **research assistant** can give encouragement approx. every 15 seconds (depending on participant).

- Great Effort
- Keep it up

1. When there is 15 seconds to go, the lead researcher will inform the participant that "In a moment I'm going to tell you to stop. When I do, just stop right where you are and I will come to you."
2. When the timer reaches 6 minutes say "Stop!" Walk over to the patient. Consider taking the chair if they look exhausted. Mark the spot.
3. Note the correct number of laps and record the distance covered.

Post-test: Measure heart rate

Appendix E

Physical Measurement Data Collection Sheet

Unique ID code		Date:
Resting BP	Heart Rate/min pre:	Heart Rate/min post:
Height 1 (m):	Height 2 (m):	Mean:
Weight 1 (kg):	Weight 2 (kg):	Mean:
B.M.I. (kg/m$^{2)}$:		
Waist Circ.1 (cm):	Waist Circ. 2 (cm):	Mean:
If unable to measure height Ulna Length 1 (cm):	Ulna Length 2 (cm):	Mean:
If unable to weigh Mid Upper Arm Circ.1 (cm):	Mid Upper Arm Circ.2 (cm):	Mean:

6 Minute Walk Test:		
20m	320m	620m
40m	340m	640m
60m	360m	660m
80m	380m	680m
100m	400m	700m
120m	420m	720m
140m	440m	740m
160m	460m	760m
180m	480m	780m
200m	500m	800m
220m	520m	820m
240m	540m	840m
260m	560m	860m
280m	580m	880m
300m	600m	900m

Distance in last lap:	Direction travelled on last lap: towards finish line ☐ away from finish line ☐
Total distance covered:	

Appendix F

Protocol for Weight, Height and Waist circumference Measurements

SOPHIE Study Protocol for Measuring Weight, Height and Waist Circumference

Adapted from WHO STEPS Surveillance (Part 3: Training and Practical Guides 3-3-1, Section 3: Guide to Physical Measurements (Step 2))

Measuring Height

1. Set up stadiometer as per instructions
2. Ask the participant to remove their:
   - foot wear (shoes, slippers, sandals, etc.)
   - head wear (hat, cap, hair bows, comb, ribbons, etc.)
3. Ask the participant to stand facing you with:
   - feet together
   - heels against the back board of the stadiometer
   - knees straight
4. Ask the participant to look straight ahead and not tilt their head up
5. Make sure eyes are the same level as the ears
6. Move the measure arm gently down onto the head of the participant and ask the participant to breathe in and stand tall
7. Read the height to 0.01m at the exact point
8. Ask the participant to step away from the stadiometer
9. Record the height measurement in centimetres in the participant's record
10. Repeat steps 1-9
11. Calculate and record mean height

Measuring Weight

1. Set up calibrated weighing scales as per manufacturer's instructions on a firm, flat surface
2. Ask the participant to remove their footwear (shoes, slippers, sandals, etc.)
3. Ask the participant to step onto scale with one foot on each side of the scale
4. Ask the participant to:
   - stand still
   - face forward
   - place arms at their sides
   - wait until asked to step off
5. Record the weight to 0.1kg on the participant's record

6. Repeat steps 1-5
7. Calculate and record mean weight

Measuring Waist Circumference

1. Ask the participant to stand behind privacy screens
2. Ask the participant to pull up clothing covering the waist
3. If this is not possible, the measurement may be taken over light clothing but not thick or bulky clothing
4. Standing to the side of the participant locate the last palpable rib and the top of the hip bone, you may ask the participant to assist you in locating these points on their body
5. Wrap the measuring tape around the participant (or ask them to do it themselves)
6. Position the tape against the skin at the midpoint of the last palpable rib and the top of the hip bone, making sure to wrap the tape over the same spot on the opposite side
7. Check that the tape is horizontal across the back and front of the participant and as parallel with the floor as possible
8. Ask the participant to:
9. stand with their feet together with weight evenly distributed across both feet
10. hold the arms in a relaxed position at the sides
11. breathe normally for a few breaths, then make a normal expiration
12. Measure waist circumference and read the measurement at the level of the tape to the nearest 0.1 cm, making sure to keep the measuring tape snug but not tight enough to cause compression of the skin
13. Record the measurement on the participant's record
14. Repeat steps 1-13
15. Calculate and record mean waist circumference