The SOPHIE

Special Olympics Programmes Health Impact Evaluation

2013-2015 Study

Report

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Abbreviations

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
BMR	Basal Metabolic Rate
cm	Centimetres
COPD	Chronic Obstruction Pulmonary Disease
CVD	Cardiovascular disease
DCU	Dublin City University
DOH	Department of Health
DOHC	Department of Health and Children
DRV	Dietary Reference Values
DXA	Dual-energy X-ray absorptiometry
DLW	Doubly labelled water
DS	Down syndrome
EAR	Estimated Average Requirement
FFQ	Food Frequency Questionnaire
FSA	Food Standards Agency
FSAI	Food Safety Authority of Ireland
ft	Feet
g	Grams
GP	General Practitioner
HEI	Healthy Eating Index-2005
HSE	Health Service Executive
ID	Intellectual Disability
IDS-TILDA	Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
IPAQ	International Physical Activity Questionnaire
kg	kilograms
lb	pounds
m	meters
Max	Maximum
Min	Minimum
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
NCI	National Core Indicators
NHIS	National Health Interview Survey
NI	Northern Ireland
PA	Physical Activity
PARQ	Physical Activity Readiness Questionnaire
PwID	Persons with an Intellectual Disability
REC	Research Ethics Committee
RD	Registered Dietitian
RDA	Recommended Dietary Allowance

RCN	Royal College of Nursing
SLÁN	Survey of Lifestyle, Attitudes and Nutrition
SO	Special Olympics
SOI	Special Olympics Ireland
SOPHIE	Special Olympics Health Impact Evaluation
SPSS	Statistical Package for the Social Sciences
STEPS	STEPwise approach to Surveillance
TILDA	The Irish Longitudinal Study on Ageing
UK	United Kingdom
US	United Sates
USDHHS	United States Department of Health and Human Services
WHO	World Health Organisation
WISP	Weighed Intake Software Package
V02 MAX	Maximal volume of oxygen consumption
6MWT	Six minute walk test

1. Introduction

Special Olympics (SO) is an international organisation which provides both sporting and social outlets for individuals with Intellectual Disability (ID). In Ireland, Special Olympics Ireland (SOI) is the most popular organization or club that individuals of any age group with ID attend. The mission of SOI is *"to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with an intellectual disability, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendships with their families, other Special Olympics athletes and the community"*, (SOI 2014). The link between physical activity and health and well-being has long been recognised with references to this dating back to the ancient Greek and Roman empires. In recent years there has been an ever-increasing international interest in physical activity and its link to health and well-being. Many countries have now adopted national and international guidelines for physical activity. Throughout the 1980s and 1990s, exercise for health benefits was highlighted in the development of health promotion materials following the first international health promotion conference, the Ottawa Charter (WHO 1986). In Ireland, the 1995 Health Promotion Strategy set exercise as a national target to promote a positive lifestyle. An accumulated 30 minutes light physical exercise was the advice given at that time (DOH 1995). In comparisons to today's national physical activity guidelines (DOHC 2009) light exercise has been replaced with moderate-intensity physical activity where the advice in 1995 fell well below the level of physical activity necessary for major health benefits. The Health Promotion Strategic Framework (HSE 2011) and "Hi! Healthy Ireland", the framework for improved health and well-being (DOH 2013), has put the onus on health professionals to take part in health promotion strategies that enhance the health and well-being of people with intellectual disabilities.

1.1 Definition

The terms physical activity, exercise, and fitness have been used interchangeably; however, the terms describe different concepts. Physical activity is the principal term used in research, with exercise and fitness used as related terms. Caspersen, Powell and Christenson (1985) defined physical activity *"as any bodily movement produced by skeletal muscles that requires energy expenditure"* (p. 126). The amount of exercise a person takes is commonly understood as a level of physical activity. Exercise as defined by the World Health Organisation (WHO 2004) has a more multifaceted meaning than physical activity and is defined as *"A subset of physical activity behaviour that involves purposive and repetitive movements"* (WHO 2004). Where exercise is a structured intermittent physical activity for a specific purpose, physical activity is a continuous state of energy expenditure that maintains life. The World Health Organisation (2009) identified physical activity as a preventative health measure that is critically important for the health and well-being of people of all ages. As the benefits of physical activity are progressively acknowledged, measuring physical activity accurately in a population is important to help identify reasons for low and high activity in order to assist and maintain recommended levels of physical activity for optimal health.

1.2 ID Prevalence in Ireland

The latest records in the Republic of Ireland show 27,691 people registered on the National Intellectual Disability Database in 2013, which represents an ID prevalence rate of 6.04 per 1,000 population (Kelly and O'Donohoe 2014). A research and information service briefing paper by Murphy (2014) identified multiple sources of data on the prevalence of learning disabilities in Northern Ireland with none of them considered definitive. He estimated that there were 26,500 people with a learning disability in Northern Ireland, with 11,898 mild/moderate, 4,468 severe and profound, giving a total of 16,366 people with a learning disability. In the Republic of Ireland 2006 Census of Population, additional questions were asked relating to disability and a National Disability Survey report was generated from the data collected (National Disability Survey 2006). Of the entire population, 9.3% (393,800) of people reported having a disability. These disabilities were further divided into categories including intellectual or learning disability. In this category. 71,600 people were recorded and of these 50,400 were diagnosed with intellectual disability. This number is significantly higher than the figure from the National Intellectual Disability Database (NIDD) which reported 25,613 people with intellectual disability (Kelly, Kelly and Craig 2007). The difference can be accounted for by the broader definition taken in the census data which would have included those with mild learning difficulties, dyslexia or specific learning disabilities not recorded in the NIDD statistics.

1.3 Health Status and ID

Research suggests that although the health of people with ID has improved over the past 30 years, there are still higher rates of both primary and secondary medical conditions, undiagnosed diseases and unmet health needs compared to the non-disabled population (McCarron et al. 2011, O'Hara, McCarthy and Bouras 2010). ID studies have highlighted unrecognised or poorly managed medical conditions varying from multiple sensory impairments, osteoporosis, reflux oesophagitis, helicobacter pylori, bowel problems, to heart and infectious diseases (RCN 2013, O'Hara, McCarthy and Bouras 2010). A scarcity of accessible health promotion material, communication difficulties, lack of professional training, absence of screening and diagnostic overshadowing camouflage many health issues for people with ID (Gates and Barr 2009).

A literature review of major health risks of ageing adults with ID by Haveman et al. (2010) suggests that variations in prevalence of diseases and health risks in ID were culturally dependent. The review uncovered health risk factors, such as inactivity and obesity as often the main link to the onset of a variety of diseases and disabilities. Where levels of poor health were found, sedentary lifestyles were recognized as a major health risk factor in ID. Evidence suggested that healthier lifestyles, more physical activity/sports, better nutrition and surveillance of health risks were ways to improve health status within populations with ID (Maguire, Daly and Smyth 2007, Havercamp et al. 2004). A study recommended future research to understand health issues and inequalities in ID and implement health promotion campaigns aimed at improving health in this population (Maguire, Daly and Smyth 2007). Several studies have concluded that while people with ID are a sedentary and overweight population, increasing physical activity/sports was a key factor essential to improve health status (Haveman et al. 2010, Havercamp, Scandlin and Roth 2004).

One of the most significant current discussions in ID is the health risks from inactivity which lead to increased risk factors for non-communicable diseases like Type 2 diabetes and heart disease (Taggart and Cousins 2014, WHO 2004). Research suggests that although the health of people with ID has improved over the past 30 years, there are still higher rates of both primary and secondary medical conditions, undiagnosed diseases and unmet health needs compared to the non-ID population (McCarron et al. 2011, O'Hara, McCarthy and Bouras 2010). The Royal College of Nursing (RCN 2013) has argued that people with ID have low rates of physical activity, poor diet and secondary health conditions that contain their abilities to be active. As a consequence, inactivity has heightened the need for health promotion where it is necessary to develop health promotion strategies and interventions designed to promote physical activity in people with ID (Marks and Sisirak 2012).

1.4 Age, older people and frailty in ID

Multi-morbidity, defined as two or more chronic conditions, has been described recently as highly prevalent in older people with ID (Hermans and Evenhuis 2014, Mc Carron et al. 2013). A number of studies of a large older ID population (n=1050) in Holland by Hilgenkamp, Van Wijck and Evenhuis (2014, 2012) suggested that ID may lead to early frailty with increasing morbidity and mortality. An increase in physical activity/sport in people with ID can help prevent loss of function and age related mobility risks associated with frailty in ID and is core to aims and objectives in SO (Hilgenkamp Van Wijck and Evenhuis 2014).

1.5 Obesity in ID

Obesity is a worldwide problem with dramatic impact on morbidity, mortality, quality of life and health care costs. The World Health Organisation now refers to the global pandemic of overweight and obesity as "globesity" (WHO, 2015). The physical, financial and emotional outcomes of these diseases can be significant for the affected person and his/her family. In addition, the costs of these morbid conditions to society for treatment can be staggering as well; it has been previously estimated that the economic impact of obesity in Ireland is around €1.13 billion annually (Dee et al. 2012). It is thought that people with ID are more likely to be overweight or obese than the general population but different sample sizes, study populations, age ranges of participants and methodologies used in studies make it difficult to accurately quantify the issue of overweight and obesity in people with ID.

The most recent statistics in Ireland come from the ID Supplementary study of the Irish Longitudinal Study on Ageing (IDS-TILDA), a first study of its kind in Europe (McCarron et al. 2014). It allows direct comparison between an Irish nationally representative sample of older adults over 40 years of age with an ID and the general population over 50 years of age. Given their reduced longevity, people with ID over 40 years of age were included. Computer assisted interviews were completed by 708 participants or proxy reporters and physical measurements were obtained for 602 participants from which BMIs were calculated (kg/m^2), Of those for whom BMI was calculated 3.2% were underweight, 30.1% were normal weight and 66.7% were overweight or obese. Older adults in the general population were less likely to be normal weight (21%) and more likely to be overweight or obese (79%) than older people with ID. Women with ID were more likely to be obese than men (69.9% compared to 62.3%). Those with a mild ID were more likely to be overweight or obese (84.9%) than those with a severe/profound ID (46.9%). Waist circumference measurements identified that 64.6% of the sample were at substantially increased risk of cardio-metabolic disease, compared to 53% of the general population.

Evidence from other countries has also found high levels of overweight and obesity in ID populations compared to non-disabled populations (Foley, Lloyd and Temple. 2013, Bhaumik et al. 2008, Melville et al. 2008). A US physical activity study of 294 adults with ID by Barnes et al. (2013) found 79.6% were overweight or obese. In France, a similar study of 570 adults with ID by Mikulovic et al. (2014) found 62.8% overweight or obese with gender a strong risk factor where both studies reported men less overweight or obese than women (Mikulovic et al. 2014, Barnes et al. 2013). Contributing factors to high levels of obesity in adults with ID include poor dietary habits and very high levels of physical inactivity (Matthews et al. 2011, McGuire, Daly and Smyth 2007). A future concern for people with ID was reported in a recent study of obesity trends of Special Olympians by Foley, Lloyd and Temple (2014). While the study was limited to a predominately active ID population (n=2541), the evidence shows obesity as a growing health concern in ID and the importance of promoting physical activity/sports as a primary means to tackle overweight and obesity.

1.6 Mental health in ID

Alongside poor physical health people with ID are at higher risk of a range of mental health disorders including anxiety and depression as well as dementia and Alzheimer’s (RCN 2013, Mc Carron et al. 2011). Emotional, nervous and psychiatric disorders were reported as diagnosed by a doctor in 60% of the sample of an Irish longitudinal study in ID by McCarron et al. (2011). However, prevalence of mental health disorders varied due to different sub-populations, methodology and diagnostic criteria and whether behaviour that was challenging was included. While self-injurious and challenging behaviours were classified as frequent secondary health conditions found in ID, a review of major health risks by Haveman et al. (2010) argued that variations and categories of health disorders were uncertain and culturally dependent. A systematic review of the effect of exercise on challenging behaviour by Ogg-Groenendaal, Hermans and Claessens (2014) indicated exercise/sports as an effective treatment for people with challenging behaviour. Like many research topics in ID, they reported low methodological quality, limited research and a need for greater research for this group of people.

1.7 Health inequalities in ID

Emerson and Hatton (2013) maintain that health inequalities occur and persist in ID yet can be addressed by change in the public health perspective, where clinical and long-lasting protective interventions provide a central role. Health inequalities were identified as a main negative influence on the health of people with ID where a review in the US by Fisher (2004) concluded that inequalities in health care place people with ID at greater morbidity and mortality risks. People with ID face multiple barriers to basic health care from health inequalities. They also face issues such as poverty, accessing health care, nutritional status, employment status, transport arrangements and housing that can result in health inequalities and social segregation (Ward, Nichols and Freeman 2010, Gates and Barr 2009, Fisher 2004).

1.8 Sedentary lifestyle

Sedentary lifestyle is commonly referred to as having little or no physical activity. In the literature, a sedentary lifestyle and inactivity were frequently used as interchangeable terms with similar meaning. Inactivity, meaning lack of physical activity denoting a sedentary lifestyle, was identified as the fourth leading risk factor for global mortality (WHO 2010, USDHHS 2008).

The Irish lifestyle surveys SLÁN 2007, 2002, 1999 (SLÁN 2007) have reported that levels of physical activity in everyday life are decreasing. Labour saving technology, safer occupational activities, modes of transport, domestic and sedentary leisure activities like TV and computers, have influenced the reduction in physical activity levels in modern populations (Hardman and Stensel 2009). Sedentary lifestyle is defined as engaging in no leisure time physical activity over a two week period, and not being active enough to achieve the health benefits of physical activity (USDHHS 2002). A sedentary level was also defined by steps taken daily, where populations with fewer than 5,000 steps per day were classified as sedentary (Tudor-Locke and Bassett 2004).

People with IDs who lead sedentary lifestyles may have fewer options or more limited opportunities to be being physical active, with a majority (93%) not obtaining recommended levels of activity (Emerson 2011). However, SO shows that with an innovative physical activity/sports intervention, people with ID can be supported in leading a more active lifestyle (Frey 2004).

1.9 Health outcome of inactivity in ID

Over the past ten years, inactivity and a sedentary lifestyle has been recognised as a significant risk factor for ill health for people with ID (Bartlo and Klein 2011, Carmeli et al. 2009, Lynnes, Nichols and Temple 2009, Moss 2009). Low rates of physical activity, along with diets high in fat and secondary health conditions, inhibit and restrain people’s ability to be active (RCN 2013, O’Hara, McCarthy and Bouras 2010, Haveman et al. 2010). In interviews of a community-based sample of 433 adult with ID, Finlayson, Jackson and Cooper (2009) found evidence that many primary and secondary health conditions found in ID were either as a result of or associated with inactivity. Inactivity was found as a major risk factor for coronary heart disease and obesity (Vis et al. 2012, Moss 2009, Melville et al. 2008). A positive correlation has been reported between low activity and overweight/obesity in people with ID (Bhaumik et al. 2008, Walsh 2005). In addition, people with ID were found to be susceptible to secondary health conditions such as diabetes, osteoporosis, constipation, and depression (Taggart and Cousins 2014). A European survey of health indicators identified people with ID as having twice as many health problems as the general population, due to primary disabilities like epilepsy, secondary issues of obesity and inactivity and syndrome-related health conditions (Walsh, Hall and Ryan 2008). Additionally, people with ID can face multiple barriers to basic health care, with health inequalities and disparities in access, communication, knowledge and quality, allowing a high risk of morbidity and premature mortality (Ward, Nichols and Freenan 2010, Fisher 2004).

1.10 ID Syndromes

Within the population of people with ID there is a complex array of syndromes and disabilities, making it one of the most heterogeneous populations found under a disability classification. While there are multiple syndromes documented in ID, Down syndrome (DS) is the most recognised and has been specifically portrayed in Special Olympians. People with DS were found to be not as active as their ID peers and had a low physical activity level, predisposing them to increased health risks over the lifespan (Pitetti and Fernhall 2004). However, people with DS had significant improvements in cardiovascular fitness, muscular strength and endurance following sports and exercise programs, as well as improvement in attitudinal and psychosocial outcomes (Rimmer et al. 2004, Heller, Hsieh and Rimmer 2004). The changes recorded were increased exercise, self-efficacy, fewer cogitative and emotional barriers, improved life satisfaction and marginally less depression. Yet people with DS found difficulties in managing their physical activity and reported access to facilities, lack of transport, high cost and lack of coaching as major barriers to participation in exercise programs (Heller, Hsieh and Rimmer 2002).

Physical activity can sometimes be neglected and overshadowed in people with autism spectrum disorders (ASD), despite the fact that physical activity can provide multiple benefits. The benefits of physical activity for an individual with ASD are in reducing stereotypical behaviour, increasing appropriate responses and providing potential social interaction. This is in addition to the general health benefits gained from being active. With increasing numbers of people with ASD, physical activity initiatives and sports benefit not just children but adults over the lifespan of an individual (Todd and Reid 2006).

1.11 Physical activity Guidelines

Over the last twenty years, scientific research has added to the understanding of physical activity, which in turn has generated a variety of physical activity guidelines designed to provide information and guidance on the types and amounts of physical activity that provide substantial health benefits. Table 1 presents an outline of the WHO (2009) recommended amount of physical activity. The guidelines set out by the US Department of Health and Human Services (2002), the American College of Sports Medicine/American Heart Association (Haskell et al. 2007) and the WHO (2009) have been adapted as a foundation for the national guidelines on physical activity for Ireland (DOHC 2009).

The Department of Health and Children (2009) produced “The National Guidelines on Physical Activity for Ireland” to support the promotion of physical activity in Ireland. The aim of the national guidelines was to emphasise the importance of physical activity for health and to outline the recommended levels of physical activity for people of all ages and abilities. The guidelines were divided into specific sections for children, adults, older people and people with disabilities. The recommendations for people with disabilities were short, not very specific, and refer back to the adult guidelines, with no focus on specific disabilities.

Short straightforward guidelines provide a clear, concise, public health message that is intended to encourage participation by a sedentary population in physical activity. A combination of both moderate and vigorous-intensity exercise over 30 minutes a day, along with activities that maintain or increase muscular strength and endurance on a minimum of 2 days each week, has become an internationally recognised fundamental guideline for adults, including adults with ID.

1.12 Physical activity measuring methodology

Temple and Stanish (2008) maintain that studies of physical activity in ID have methodology limitations. They identify 3 main limitations: small sample size, over reliance on people with a mild level of ID and difficulty in obtaining a rigorous analysis. They argue that studies have no match or control groups and it is difficult to generalise to the wider population. Frey, Stanish and Temple (2008) argued that there are significant methodology limitations that restrict clear conclusions in recording physical activity levels in ID. One of the main difficulties in physical activity studies in ID is the difficulty in obtaining a sample size sufficient to conduct meaningful statistical analysis.

1.13 Sports and SO

Draheim, Williams and McCubbin (2003) suggested that SO provides physical activity opportunities and is a valuable resource for people with ID in order to be physically active. Social support and motivation was a key driving force in sports for people with ID (Farrell et al. 2004). Shapiro (2003) argued that task orientation and social integration were the main participation motives of SO athletes. Factors that help motivate ID individuals in sports were positive feedback, choice, learning skills, showing ability, friends, social approval and fun (Harada and Siperstein 2009).

1.14 Physical activity interventions

A global priority in public health has identified the need to establish physical activity interventions that are sustainable and designed to target different groups (Foster et al. 2011, WHO 2004). While Mc Dermott et al. (2012) argued that interventions need to be specifically designed for people with ID to improve their poor health profile, a literature review by Bartlo and Klein (2011) suggested that physical activity programmes are not available, accessible or adaptable and are short lived and difficult to maintain for an ID population. Yet, several physical activity interventions in ID have reported a range of benefits such as improvements in BMI, strength and balance and benefits in quality of life and social competence (Hobbs et al. 2013, Heller, Hsieh and Rimmer 2004). However, interventions for people with ID appear limited, in contrast to interventions reported in the non-ID population. Evidence suggests that such physical activity interventions are not readily available for this population, the effects are limited and difficult to maintain, with poor prospects of studies being generalised (Dowling et al. 2012a, Bartlo and Klein 2011). Studies have recommended that physical activity interventions in ID now need to be developed and translated into practice and walking has been identified as a potential key activity (Mc Dermott et al. 2012, Bartlo and Klein 2011).

1.15 Access to physical activity

Studies consistently argued that lack of accessibility, which reduces opportunities to be active, was the foremost barrier to physical activity in ID (Walsh, Hall and Ryan 2008, Temple 2007) and the least active individual had no access to physical activity options (Heller, Hsieh and Rimmer 2004). While the lack of access may appear straightforward to confront, access barriers in ID were often invisible, not clearly identifiable and part of a wider mobility issue, where physical activity characteristics such as the complexity of a task or the pace of an activity was too difficult for the individual with ID (Yalon-Chamovitz 2009). Early studies found that adults with ID who had access were engaged in only small amounts of physical activity, classified as passive activities comparable to sedentary behaviour (Thornton and Collins 1986). Two decades later, a study of leisure provision of 160 people with ID by Zijlstra and Vlaskamp (2005) found that watching television and listening to music were identified as common activities that people were largely dependent on, referring to it as empty hours rather than quality time. People with ID are involved in a low amount of activities in general with Draheim, Williams and McCubbin (2002) reporting that 49% of their study population had no leisure activity.

1.16 Evidence of impact of SO

SOI has been working to meet the recreational and sporting needs of people with intellectual disability for many years. Membership of SO has been building since it began in Ireland 34 years ago and has ~ 10,000 athletes with intellectual disability across the island. Supported by a team of volunteers, SO has become more than a sporting organisation as it works towards supporting people in their overall health and well-being (Dowling et al. 2010). Promoting athletes' health is an important remit for SOI, with programmes such as the Healthy Athlete Programme offered to them; this includes vision and hearing screening as well as more general health promotion. SOI recently launched a new health promotion programme offering resources to athletes and clubs (SOI 2016). SO clearly plays an important role in providing access to sporting opportunities for persons with ID but anecdotally the benefits of participation in SO programmes in terms of health and well-being are reported, with some evidence for health and well-being emerging.

A mixed methods study (SO, 2005) which implemented a community-based health promotion program for SO athletes in sites in the US, Kenya and Mauritius found that athletes experienced many positive health benefits, with the most common findings being an increased percentage in normal body weight, increased exercise knowledge, improved confidence in exercise, improved hygiene and increased participation in SO activities.

Some similar benefits have been documented in several studies from a range of different countries around the world. The work includes a number of studies (Harada et al. 2008a, Harada et al. 2008b, Siperstein et al. 2005) which used the same methodology in the USA, Argentina, Brazil and Peru, to explore motivations of athletes to participate and/or leave SO, the importance of SO as perceived by families and coaches and the impact of participation in SO. Qualitative telephone surveys were administered to athletes (n= 579 USA, n=49 Argentina, n=213 Brazil, n=118 Peru, n=223 China), and family members (n=1307 USA, n=130 Argentina, n=506 Brazil, n=174 Peru, n =331 China) and coaches (USA n=300, China n=89). The findings across these countries were similar overall, with fun, socialising, winning competitions, making new friends, playing sports, exercise and being healthy cited by athletes in all locations as the main motivations for participating. Barriers to participation included lack of information about how to find SO post-school and loss of interest in SO. Other impacts included improved self-esteem and confidence, social skills and friendships, better health and sports skills. Coaches felt that participation would be enhanced with better communication and more information from SO, better use of media for advertising by hosting invitational events/open days. Other studies have examined the impact of SO programmes using a mainly qualitative approach.

Such studies include a study by Dowling et al. (2010) which found that SO programmes provide an opportunity for young people with ID to connect with the wider community through a shared interest in sport and operates through a complex dynamic of connections at three levels; people participating in the programme, the organisation underlying it and the interaction with local community.

Another qualitative study (Kersh and Siperstein 2012) which aimed to explore how involvement in SO benefits the families of athletes, conducted telephone interviews with 120 families of SO athletes and 49 athletes. Questions addressed family members' perceptions of the athlete, the impact that SO has on the athlete, family member involvement in and experiences of SO and the impact of SO on the family. The study found that families expressed great pride in their athlete's accomplishments, families recognised the value of SO for the social development of athletes and families reported high levels of involvement in SO such as volunteers, chaperones and coaches. Families also felt that SO provided opportunities which strengthened relationships within the whole family, and allowed them to socialise within new circles in the community.

Research commissioned by SO (2005) which screened more than 3,500 SO athletes found that athletes have more serious health problems than the general population. Thirty percent of athletes failed hearing tests. This rate was up to six times higher than rates seen in the general population. One-third of the athletes required eyewear. Twenty-nine percent of males and 13 percent of females screened had below normal Bone Mineral Density (BMD). Half of the athletes screened had one or more foot diseases or conditions (e.g., bunions, corns, calluses, fungal infection, ingrown nails, etc.). In this relatively young athlete population (average age 27 years), 30 percent of adults were obese and 23 percent overweight.

The available evidence of a health and well-being effect of SO programmes has been limited by the fact that the benefits have not been captured in any robust study using a combination of objective and subjective measures to compare the impacts of athletes directly with a comparable group (i.e age and sex matched persons with ID who do not take part in SO programmes). In the SOPHIE project, we set out to undertake an evaluation of health and well-being using a mixed methods approach in persons with ID who take part and do not take part in SOI programmes.

2. Methodology

2.1 Aims

The primary aim of the study was to explore whether people with IDs who take part in SO are healthier and happier than people with IDs who do not take part in SO programmes. Barriers to participation in SO were also explored. A secondary aim was to examine if there are any wider impacts on the families of athletes in terms of health and well-being. A third aim of the research was to review the costs of delivering SOI programmes and to explore the value generated.

2.2 Objectives

- To recruit persons with an ID matched by age, sex, level of disability and ambulance from the same care settings who take part and do not take part in SOI programmes.

- To compare self-rated health related quality of life measures between those with an ID who take part and do not take part in SOI programmes.

- To compare self-rated health related quality of life measures between family carers of those with an ID who take part and do not take part in SOI programmes.

- To conduct a comparison of the levels of participation in sport and physical activity and physical fitness between individuals with ID who take part and do not take part in SOI programmes.

- To compare self-rated nutrition intake and measures of anthropometry (waist, weight, height) between those with an ID who take part and do not take part in SOI programmes.

- To evaluate the cost of providing SOI programmes to athletes in the Republic of Ireland and to explore the value generated.

- To explore the barriers to persons with ID participating in SOI programmes

- To explore the extent to which SOI programmes systematically address the barriers to participation which have been identified in a recent literature review which examined the barriers for persons with ID in undertaking physical activity.

- To identify strategic recommendations to inform future policy and planning within SOI.

2.3 Methods

The project commenced in July 2013 and took two years to complete. It involved 146 people with intellectual disability who were recruited from five services in the Republic of Ireland supporting people with intellectual disabilities. 146 of their family carers also took part in the study. The researchers employed a mixed methods approach, using both quantitative and qualitative methodologies. A cross-sectional study design was used. **Six separate reports are presented as part of this report; each one outlines the specific aims and methodologies employed in detail. Hence, only an overview of the methods is provided in this section.** Approval was granted at each of the care services to facilitate access to clients with intellectual disabilities who take part and do not take part in SO Programmes. A link person was appointed at each of the centres to work closely with the study team. Ethical approval was obtained from the Research Ethics Committee at Dublin City University (DCU) (Reference no. DCUREC/2013/148) and at the local sites, as appropriate.

Every effort was made to try to ensure that the participants were matched by age, sex, level of disability and level of ambulance within services, so in theory, the only difference between them was that one group takes part in SOI, while the other group does not. We conducted detailed interviews with the athletes and non-athletes, which included questionnaires and physical measurements. This consisted of the EQ-3D-5L (EuroQol Research Foundation 2016), (capturing health related quality of life), the SLÁN survey (SLÁN 2007), (capturing health status and health service use) and the International Physical Activity Survey (IPAS), (International Physical Activity Questionnaire 2002), (capturing physical activity levels). The surveys were administered directly face-to-face with participants assisted by their principal family carer, where required. All instruments were modified to be ID friendly, with pictorial representations depicting key concepts being examined. The physical measurements included a resting blood pressure reading, weight, height and waist circumference measurements. Physical fitness levels were assessed using the 6-minute walking test. All participants were asked to wear an accelerometer/sensewear devise to measure physical activity levels over one week. Nutrition intake was assessed using 4-day food diaries. Family carers completed an EQ-5D-3L on behalf of the athletes and non-athletes (proxy report) and one on their own behalf. Family carers also completed an amended form of SLÁN (2007) about their own health status and health service usage. **All of the references and questionnaires are available from SOI on request.**

Qualitative interviews were conducted with athletes, non-athletes, family carers and care staff. Participants were recruited from urban and rural day and residential care services for persons with ID in the Republic of Ireland. SOI management staff took part in a focus group interview to examine how the organisation has addressed barriers to persons with ID undertaking physical activities, identified in a previous study.

The physical measurements were collected in large data sweeps by the research team in suitable venues in close proximity to or in the services where they were recruiting. A qualified nurse was in attendance for all data collection sweeps to provide whatever support was needed to families and in case of injuries or incidents. As part of the preparatory work the research team met with “Inclusion Ireland“ an advocacy group, who advised them on how to make the study literature ID friendly. This included advice on the content and visual aspects of the questionnaire, as well as topic guides, and on the acceptable respondent burden. A Professor of Learning Disability Psychiatry also provided advice to the study team at the outset of the project on issues around consent, assent, giving results, and acceptable respondent burden during interviews.

Our aim was to recruit 400 people, 200 existing SOI participants who had been actively involved in SOI programmes for a period of not less than one year and 200 non–SOI participants.

2.4 Pilot Testing

A pilot study was carried out at the outset of the project to test the feasibility of the instruments and physical measurement and the practicalities of interview collection. A group of 10 Special Olympic athletes with an ID and their family members participated in the pilot study. Study instruments were administered and physical measurements were obtained, including weight, height and waist circumference.

Feedback was obtained and relevant amendments were made to study instruments. The collection of physical measurements was deemed feasible and acceptable to participants. Changes were made to the planned sequence of data collection to ensure that no participant was idle during the interview as this led to some participants becoming bored. Instead, we had to ensure that both the principal participant (athletes and non-athletes) and family carers were occupied throughout the entire interview. It was intended to administer each instrument to the participants at the same time and move together with the supervision of researchers; however, it was identified that each family was unique and varied in their speed and ability to answer questions. One-to-one assistance was deemed necessary to complete the study instruments, at each individual’s own pace. This was implemented and taken into consideration when planning data collection events.

Members of the research team working in the area of ID provided training to the research team in interviewing people with ID, to minimize potential sources of error and to improve the overall research experience for study participants. Training on anthropometry was provided to members of the team by one of the team members who is a Registered Dietitian.

Each of the participating services was asked to indicate the number of individuals with an ID attending their service and, if possible, identify those that are involved in SO programmes. Based on the profile of athletes at each care service we were able to identify and match by age, sex, level of disability and level of ambulance, those individuals attending the same service who were non-SOI athletes and invite them to participate.

Our inclusion criteria included participants registered with a service for people with ID, who met the following inclusion criteria; people with an intellectual disability, ambulant or non-ambulant, over 16 years of age with verbal communication skills sufficient to provide information about themselves, and a family member who was willing to accompany them to provide this information. While participants were asked to provide assent to take part, a family member was required to consent on their behalf. Exclusion criteria included any participant who lacked the verbal communication skills to provide information about themselves and/or not having a family member to provide this information. Information about the project was given verbally as well as in writing and potential participants and /their family/carers were given an opportunity to ask questions about the research. All participants received a print out of their own results from the data collection days presented as a “certificate of taking part”.

2.5 Setting

Four ID service provider organisations in the Republic of Ireland agreed to facilitate access to a sampling frame. These included urban and rural based populations in Dublin, Mayo and Cork. Suitable venues, which necessitated a 20 metre sports hall with non-slip flooring, were booked to conduct the research interviews with participants and their family members.

2.6 Recruitment Process

Each participating ID service provider appointed a ‘link person’ to liaise with the study team. The number of service users over 16 years of age registered with each service provider organisation who met our inclusion criteria was shared with the research team. Anonymized or minimal information was shared with the research team to allow for recruitment, adhering to data protection laws. This data was then entered into a Microsoft Excel spreadsheet and a research randomizer software package was used to randomly select potential participants to invite to participate in the study. Study information in an easy read format, including an information sheet and a frequently asked questions sheet, was developed and distributed to the selected individuals either in the post or through service provider staff, depending on the service providers’ preferred option. Permission was given by interested families to be contacted by phone and during this time queries were answered and follow up arrangements made to proceed to data collection. Refusal rates were high, however, and recruitment was slower than expected, so we placed advertisements in local newspapers and conducted radio interviews in a local radio station.

2.7 Ethical issues

Ethical approval for this study was obtained from the Ethics Committees of Dublin City University (REC reference: DCUREC/2013/148) and one service provider site who had their own ethics review panel. The other ID service provider organisations did not have an ethics committee and accepted DCU ethical approval. The main ethical issues identified were possible poor comprehension, literacy and verbal communication skills. We addressed these in the following way; assent was obtained from all people with intellectual disability and consent was obtained from all family members. Assent/consent forms were developed in an easy read format in consultation with an ID advocacy group with experience advising research teams. Each step of data collection was explained to participants by a member of the research team. Participants and their family members marked which aspects of the study they agreed to and signed consent forms before participating in the study. Participants with literacy issues marked an 'X' indicating their willingness to participate, this was witnessed by two researchers. All family members were asked to sign a consent form on their own behalf and on behalf of their family member with an ID. All participants were informed that they may withdraw at any stage, say "no" to any part of the study and that all information provided would be confidential. In addition, Garda clearance Ireland was obtained for all of the research team members who would be engaging with participants.

2.8 Overall response rates

Two hundred and ninety-two participants took part in this research study overall; this included 146 primary participants (101 athletes and 45 non-athletes) with an ID and 146 of their principal family carers. 131 of these were recruited from care services in the Republic of Ireland (See table 1). A further 15 athletes were recruited from SOI clubs in the greater Dublin area. The main reasons for declining participation were: having no family member willing or able to participate with the person with ID, family illness, busy schedules, competing priorities, burden of care, that participation could not be facilitated in the family's own home and lack of interest. 58.2% of the recruited primary participants (athletes and non-athletes) 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 reported a mild ID, 46.1% were reported moderate, and 6.4% were recorded as having a severe ID. Most of the principal family carers recruited (70%) were female, and most (76%) were parents. Other carers included 27 siblings, and 4 others (1 niece, and 3 sisters-in-law). The mean number of hours of caring per week was 57, with a median of 28. Table 2 shows the characteristics of the athletes and non-athletes. **The number of participants in each of the sub-study groups varies and they are presented separately in each individual report.**

Table 1: Number of individuals with ID invited to participate and response rates from each service provider organisation or SOI club

Service Provider	Location	No. Invited	Total (n)	Total (%)
Centre A	Urban	723	34	4.7
Centre B	Rural	432	38	8.8
Centre C	Urban and Rural	500	46	9.2
Centre D	Urban	185	13	7.0
Total		1,840	131	7.1
SOI clubs[1]	Urban	Anybody joining SOI in greater Dublin area	15	
Total recruited			146	

These additional 15 athletes recruited from SOI clubs only took part in report 2 - Physical activity and Fitness levels[1]

Table 2: Show the characteristics of the athletes and non-athletes by age, gender and level of ID.

	Total pop. (n)	%	SOI (n)	%	Non SI (n)	%
Gender						
Male	85	58.2	64	63.4	24	46.7
Female	61	41.8	37	36.6	27	53.3
Age categories						
16-29 years	43	29.5	34	33.77	9	20.0
30-44 years	77	52.7	52	51.5	25	55.6
45-64 years	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

3. Report 1: SOPHIE (Special Olympics Programmes Health Impact Evaluation) Study: Health related quality of life and health status.

3.1 Introduction

Self-rated health and quality of life measures are used as valid indicators of a person's health status. Studies show that self-rated, health-related quality of life consistently predicts adverse health outcomes (Brown et al. 2015, Dominick et al. 2002) and can be an independent predictor of mortality in older people (Verropoulou 2014, Idler and Benyamini 1997).

Measuring quality of life is complex in people with disability. People with disability may construct health, or the self-rating process, differently than those with no disability (Zubritsky et al. 2013, Drum, Horner-Johnson and Krahn 2008). Indeed, people with disability may consider health as being able to function well, rather than the absence of illness (Hofoss 2004). Previous research shows that determinants of quality of life in people with disability include physical health and functional well-being, psychological well-being, social relationships and environment, and having a disability (Hofoss 2004, Hughes et al. 2003, Tate et al. 1997, Power, Harper, and Bullinger 1999). There is relatively little work on the measurement of quality of life in people with intellectual disability. There is one previous Irish study, examining quality of life in adults with IDs (Boland, Daly and Staines 2009). There is evidence that quality of life can be reliably measured in people with intellectual disability (Verdugo et al. 2014, Golubović and Škrbić 2013).

3.2 Aim

The primary aim of this sub-study was to compare self-reported health-related quality of life in people with ID who take part in SO, and compare these with people with ID who do not take part in SO. A secondary aim was to compare proxy reported (by principal family carer) health-related quality of life in people with ID who take part in SO, and compare these with people with ID who do not take part in SO. A further aim of this sub-study was to compare self-reported health-related quality of life of the principal family carer of people with ID who take part in SO, and compare these with the principal family carer of people with ID who do not take part in SO. Finally, we wanted to examine general health status and health service usage in athletes, non-athletes and their principal family carer.

3.3 Methods

This study used the EuroQol instrument, EQ-5D-3L as the main measure of quality of life (EuroQol Research Foundation 2016). This instrument was selected as it is cognitively straightforward and only takes about two minutes to complete. Permission was granted from the EuroQol Research Foundation to use the instrument. Health-related quality of life, as measured by EuroQol, strongly correlates with the parameters of vitality, general health and mental health measured by the SF-36 method and the OPCS disability scores (Picavet and Hoeymans 2004, Tidermark et al. 2003, Brazier et al. 1996, Myers and Wilks 1999). In addition, a health thermometer was completed, using a visual analogue scale. The Medical Outcomes Study (MOS) vitality subscale was also measured, as part of the overall SLÁN survey (SLÁN 2007), administered, and scored using the RAND scores (Hays, Sherbourne and Mazel 1993). The EQ5DL score were weighted using the UK weights derived by Dolan (Dolan 1997). Athletes and non-athletes completed a self-reported EQ-5D-3L questionnaire across five domains of health which included Mobility, Self-Care, Usual Activities, Pain/Discomfort and Anxiety/Depression on their own behalf to examine how they rated their own health. Family carers were not permitted to assist them with this task as we wanted it to be independent of the family carer's viewpoint. The research team provided whatever support was needed instead to the participants. Family carers also completed an EQ-5D-3L on behalf of the athletes and non-athletes (proxy report) to compare the responses of the person with ID with those provided on their behalf by their principal family carer. Family carers of both athletes and non-athletes also completed an EQ-5D-3L about their own health-related quality of life.

Health Status, as captured in the SLÁN 2007 survey by patterns of illness, was also explored. 17 categories in total were examined including asthma, chronic bronchitis, chronic obstructive lung (pulmonary) disease, emphysema, heart attack, angina, stroke, rheumatoid arthritis (inflammation of the joints), lower back pain/other chronic back condition, diabetes, high blood pressure, high cholesterol, cancer (malignant tumour, also including leukaemia and lymphoma), urinary incontinence, problems in controlling the bladder, anxiety, depression and epilepsy.

Health service usage questions derived from the SLÁN 2007 questionnaire were administered to athletes, non-athletes and their family carers. The data was entered into Excel from the completed questionnaires and was analysed by the statistical package R. Linear regression was used to examine relationships between variables collected from the different questionnaires.

3.4 Results

3.4.1 Response

131 (7.1% response rate) primary participants with an ID and their family carers agreed to take part in this sub-study, exploring self-reported/proxy-reported and carer self-reported health related quality of life. This included 88 athletes and 43 non-athletes and their family carers. 58.8% of participants were male and 41.2% were female, with a mean age of 34.5 years. Just under half (45.8%) of the population had a mild ID, 45.8% were considered to have a moderate disability, and 4.6% had a severe ID. Of these, 117 self-completed the EQ-

5D-3L questionnaire. For 121 participants an EQ-5D-3L was completed by their carer (proxy report). Of the carers who took part, 129 self-completed an EQ-5D-3L.

3.4.2 Carers

Most carers (70%) were women, and most (76%) were parents. Other carers included 27 siblings, and 4 others, one niece, and 3 sisters-in-law. The mean number of hours of caring per week was 57, with a median of 28. A total of 23 people reported caring 24 hours a day, 7 days a week. 44 people reported caring for 10 hours a week or less. Figure 1 shows the distribution of reported hours per week spent caring.

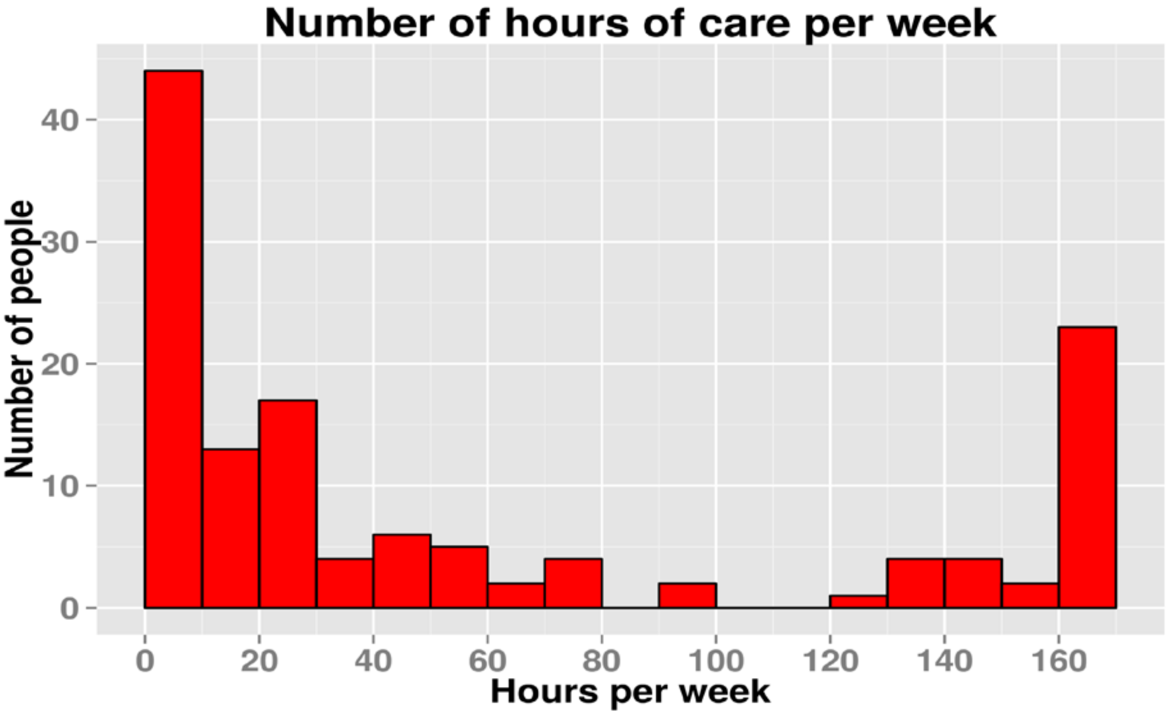


Figure 1. Number of hours spent in caring per week, as reported by family carers.

3.4.3 Quality of Life

Figures 2 and 3 show the distribution, respectively, of the self-completed, and the proxy completed (carer completed) EQ-5D-3L scores for the study participants, divided into those who are in SO, and those who are not.

Figure 2: Carer (proxy)-completed EQ5D3L on behalf of the study participants (athletes and non-athletes)

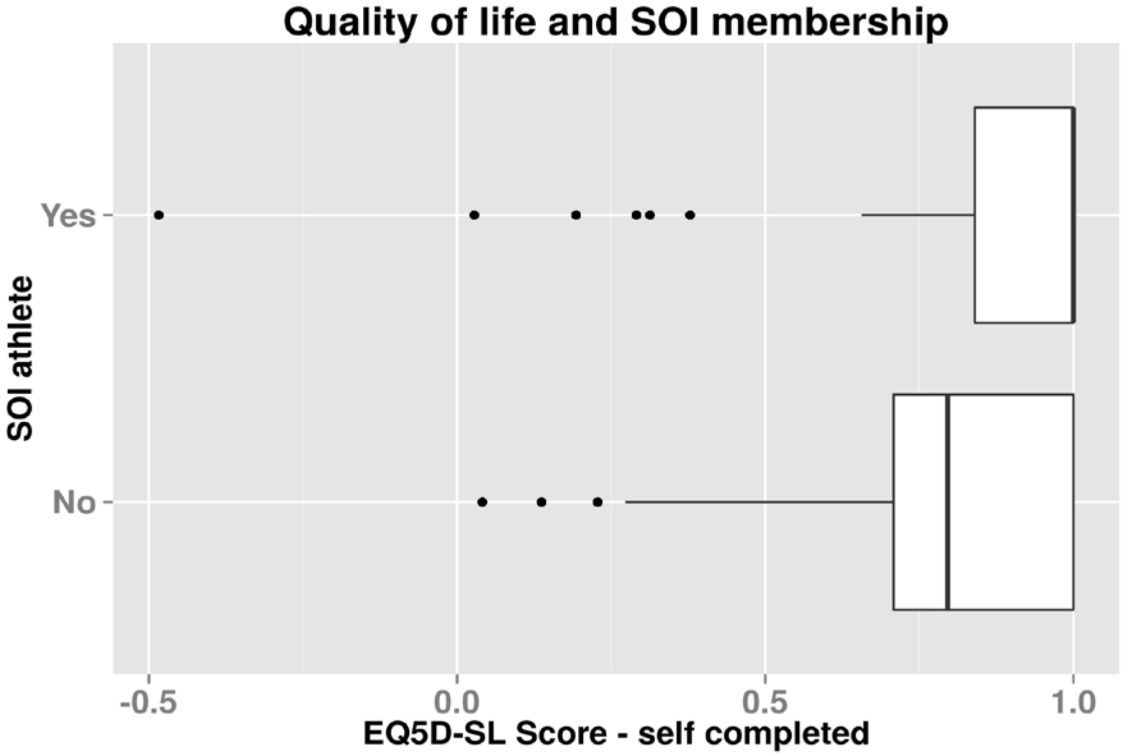


Figure 3: Self-completed EQ5D3L by the study participants by their SOI participation status

The EQ-5D-3L scores for family carers (self-completed) are shown in Figure 4 below, again divided into two groups, those whose dependents took part in SO, and those whose dependents did not.

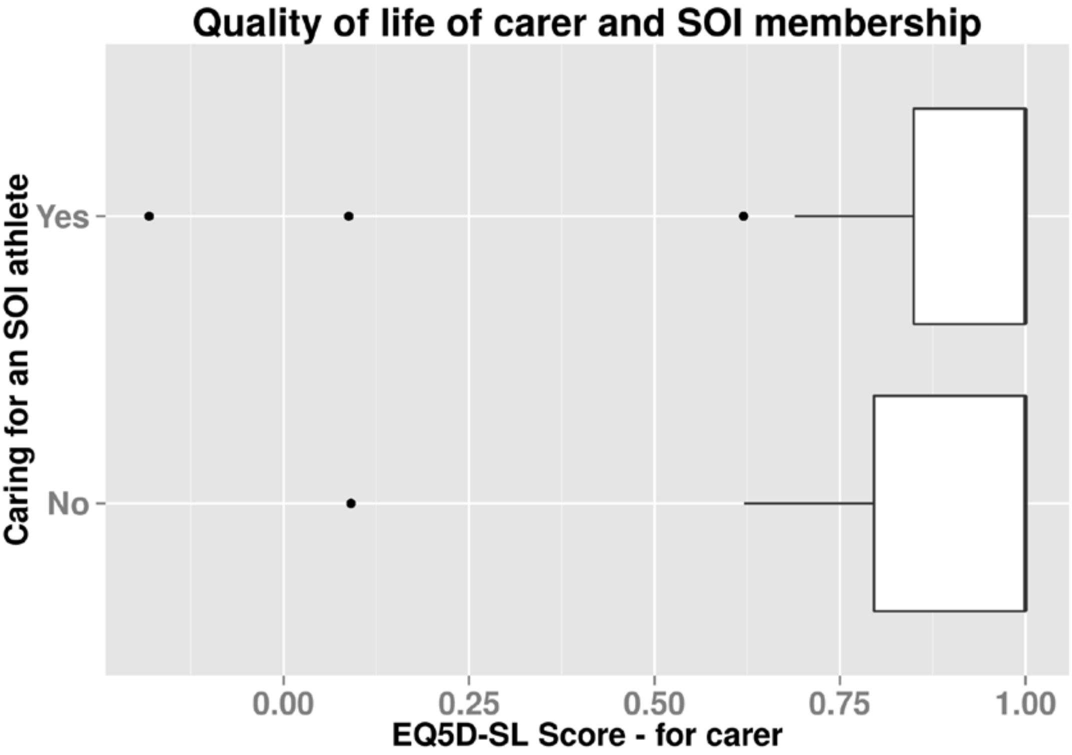


Figure 4: Carer EQ5D3L (self-completed) by SOI participation status.

There are quite large differences between the two groups, SO athletes, and non-athletes, in the mean values of both self-reported (difference = -0.12, t = -2.3, df = 54.49, p = 0.03), and proxy (carer) completed (difference = -0.22, t = -4.35, df = 44.73, p = 7.77 x 10^{-5}) EQ-5D-3L scores. The mean scores for the two groups of carers (of athletes and non-athletes) are similar (data not shown).

Further analyses of quality of life and data gathered in the accompanying questionnaires were conducted using linear regression. These were done separately for the self-completed EQ-5D-3L scores and the carer (proxy) completed scores for the study participants. These are shown in the following tables, 1 and 2.

Table 1. Primary participant (self –reported) data showing the relationship between EQ5D3L scores and related variables collected in the SOPHIE study questionnaire.

Fitting linear model: EQ-5D-3L ~ SOI + VAS + Mobility + Cooking skill.

Parameter	Units	Estimate	Std. Error	t value	Pr(>|t|)
SOI Participant	Yes vs. No	0.064	0.031	2	0.044
Health thermometer	1 IQR change	0.065	0.02	3.2	0.002
Mobility	Aided vs. Unassisted	-0.54	0.2	-2.7	0.0087
Cooking Skill	Poor vs. Average vs. Very Good	0.032	0.021	1.5	0.13
(Intercept)		0.5	0.098	5.1	1.6e-06

Table 2.EQDL (proxy reported) on behalf of athletes and non-athletes showing the relationship between EQ-5D-3L scores and related variables collected in the SOPHIE study questionnaire

Fitting linear model: EQ-5D-3L.B ~ SOI + LLTI + ID_Severity + Mobility + VAS + Visits.Yr

Parameter	Units	Estimate	Std. Error	t value	Pr(>|t|)
SOI Participant	Yes vs. No	0.065	0.027	2.4	0.017
Limiting long-term Illness	Yes vs. No	0.11	0.037	3	0.0033
Level of Intellectual disability	Moderate vs. Mild	-0.035	0.032	-1.1	0.29
	Severe vs. Mild	-0.25	0.14	-1.8	0.072
Mobility	Aided vs. Unassisted	-0.38	0.14	-2.8	0.0061
Health thermometer	1 IQR change	0.038	0.017	2.2	0.032
Health care use	10 extra visits	-0.0066	0.0034	-1.9	0.059
(Intercept)		0.51	0.1	5	2.9e-06

For both regressions there is a significant effect of taking part in SO on quality of life. The other factors included in the model are a little different. Mobility, and the score on the EQ-5D-3L Health thermometer (a visual analogue scale) is important in both evaluations. For study participants, better self-reported cooking skills had a modest effect in the model (and these were closely linked with reported patterns of food preparation). For carers, health, both in terms of long-term illness and health service use were important, as was the level of intellectual disability.

The link between the two measures of quality of life, self-reported and carer completed, is not especially close (Figure 5). Note that the lines of agreement shown on the plot are misleading, as the score is limited to 1 at the upper limit, and so the maximum possible difference falls with the mean.

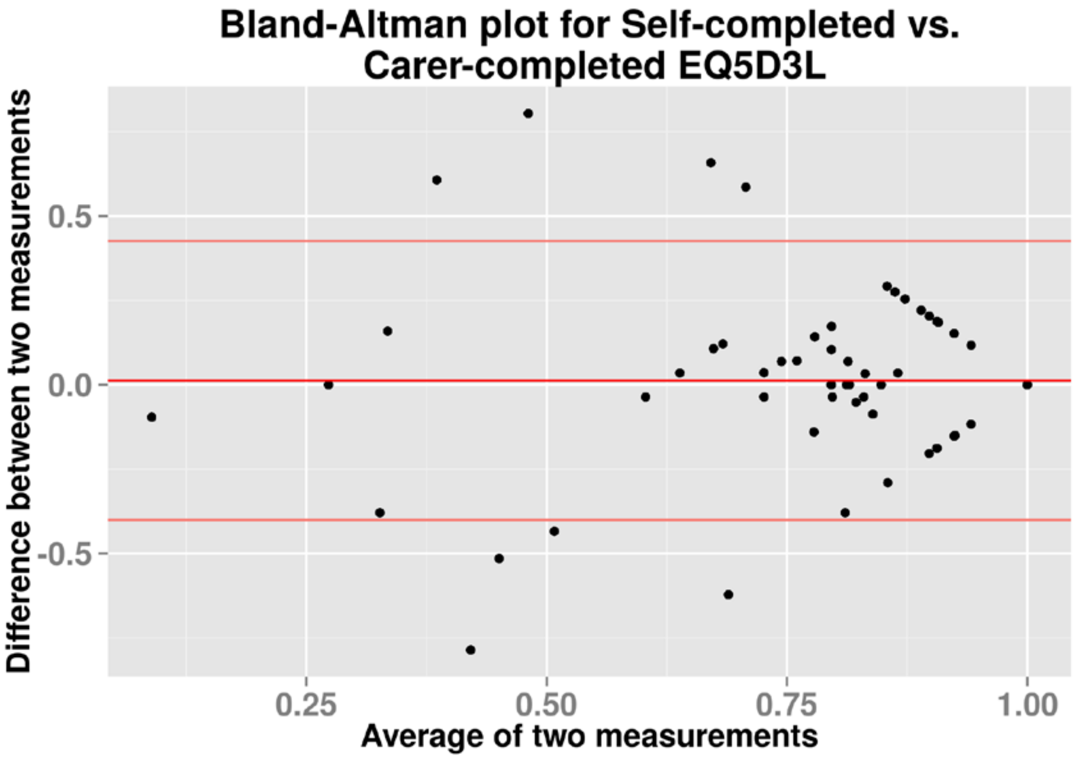


Figure 5. Link between the self-reported and carer (proxy) reported EQ-5D-3L scores.

3.4.4 General health (patterns of illness)

In the study of participants with ID the commonest illnesses reported were anxiety (12 cases), depression, and difficulties with urinary continence (10 cases each). Seven people were reported to be affected by epilepsy, 6 with low back pain, and 5 with asthma. Among carers, the commonest illnesses were high blood pressure (29 cases), and low back pain (25 cases). Thirty-four reported having raised cholesterol. Arthritis was reported by 16 people and anxiety by 11. Non-athletes reported higher rates of depression (p=0.07 Fisher's exact test) and epilepsy (p= 0.04 Fisher's exact test) than SOI athletes. No differences were recorded in individual illness frequency between carers of athletes and non-athletes.

3.4.5 Health care utilisation

The number of visits to, or from, health care providers was also recorded. Among study participants (athletes and non-athletes), there was great variation, both in visits in the last 30 days, and in visits over the last year. The mean number of visits in the last 30 days was 1.54, but the range was from 0, by far the commonest value, to 30. For the number of visits over the last year the mean was 15.96, but the range was very wide, from 0, which was just the most common value, to 274. Those few participants with very high numbers of visits had many visits from home helps, nurses, or physiotherapists. There were no statistically significant differences in overall service use between those who participated in SO and those who did not.

For carers, the mean number of visits in the last 30 days was 0.6, and the range was from 0, by far the commonest value, to 8. For the number of visits over the last year the mean was 5.47, but the range was very wide, from 0, which was still the most common value, to 115. The people with high numbers of visits over the last year used a variety of services, including GP's, psychologists and social workers. Again, there was no difference in overall service use between those whose dependents took part in SO and those who did not (data not shown).

3.5 Discussion

We have examined measures of quality of life and general health (patterns of illness) in study participants; the effect of participation in SO on both measures has not been described previously.

In this report we have found a difference between self-reported quality of life measures using the EQ-5D-3L instrument between those who take part and do not take part in SOI programmes. This difference was statistically significant. We also report a difference between the two groups when the EQ-5D-3L was completed by a family carer (proxy respondent) on their behalf, which again was statistically significant. No difference was reported, however, between scores of family carers of athletes and non-athletes, perhaps indicating that the effect on self-reported health related quality of life (if real) does not translate to family carers. We cannot extrapolate from these findings that being a member of SOI confers an improvement in health-related quality of life to participants, only that they reported it in this study - this current study design did not test “cause and effect” and further research using a longitudinal study design with pre and post participation measures would be needed to demonstrate that any improvement in quality of life is indeed caused by SOI participation. Nevertheless, these results are encouraging. The same conclusion would have to be drawn about the difference in reported levels of depression between athletes and non-athletes found in the study. Perhaps people with depression and epilepsy are less likely to take part in SOI programmes in the first place and this may account for the differential.

In participants, levels of mobility were associated with EQ-5D-3L scores as were better food preparation and cooking skills: perhaps this is related to higher levels of autonomy and independence. The EQ-5D-3L Health thermometer (a visual analogue scale) score was also important in both evaluations.

For carers who completed a proxy EQ-5D-3L on behalf of participants, mobility, level of disability, long-term illness and frequency of use of health services were important determinants of EQ-5D-3L scores.

3.6 Conclusion

The sample of people with intellectual disabilities who take part in SOI programmes reported a higher health-related self-reported quality of life status than those who do not take part in SOI programmes. Self-rated health-related quality of life measures are increasingly being recognized as a valid indicator of a person's health status. Studies show that self-rated, health-related quality of life consistently predicts adverse health outcomes. Further research using representative groups is now warranted. The greatest challenge to this study was the low response rates. While people with intellectual disability can be a difficult group to study, the response rate is so low that little beyond a direct description of study participants can be relied upon.

4. Report 2. SOPHIE (Special Olympics Programmes Health Impact Evaluation) Study: Physical activity and Fitness levels

4.1 Introduction

Regular participation in physical activity (PA) is widely acknowledged as being important for primary and secondary prevention of an array of conditions such as several chronic diseases, including obesity, coronary heart disease, hypertension, Type 2 diabetes, osteoporosis, depression and colon cancer (Marshall, McConkey and Moore 2003, Thompson et al. 2003, Bonaiuti et al. 2002, Blumenthal et al. 1999, Evans 1999). It can also reduce the risk of premature death (Warburton, Crystal and Bredin 2006). This is particularly beneficial to those with an ID who are at a greater risk of co-morbidities of respiratory disease, cardiovascular disease and cancer. Macera et al. 2003, Prasher and Janicki (2009) found that inactive people are twice as likely to develop/die from chronic heart disease as active people. Rippe et al. (1988) highlights that even if a person was to perform activities of low to 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 cardiovascular disease. People with disabilities who are more physically active tend to visit doctors less and have fewer medical complications according to the National Disability Authority (Hannon, Fitzsimon and Kelleher 2006). The psychological 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 (2009) reveals that PA increases well-being by increasing pride in physical accomplishments, improving body image and promoting more self-confidence. Particularly for persons with disabilities, it 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 (2010) proved 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 (Haskell et al. 2007) 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-intensity PA (MVPA) is acceptable. The National Physical Activity 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 (Dillon et al. 2010, Panerai et al. 2009). The proportion of people with ID who are overweight or obese also appears to be higher compared with the general population (Marshall, McConkey and Moore 2003, Martin, Roy and Wells 1997, Prasher 1995).

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 SLÁN (SLÁN-06, 2006) found that a high proportion of the Irish population do not meet the minimum PA guideline, a report by Hannon, Fitzsimon and Kelleher (2008) who did 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; 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 found to be less likely to undergo PA of any type including leisure, housework or work 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 Irish ID population with research showing that people with ID are less physically active than the general population worldwide (Temple 2007, Stanish, Temple and Frey 2006, Robertson et al. 2000). 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 benefits people with an 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 found statistically significant decreases in individuals' weight, BMI score, BMI category, and significant positive improvement in V-shape sit and reach test, sit-up in 30s and 60s tests.

A case study carried out by Escobar et al. (2013) looked to examine 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 (p value not given) 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 VO2 performance and strength of adults (mean age 39.4 years) with mild to moderate Down syndrome (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 12% increase ($p<0.01$) and a 14% increase in strength ($p<0.0001$). Carmeli et al. (2005) conducted a randomised control 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) 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, 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 viii) a lack of a culture of general participation in physical exercise and sport in Ireland.

SO is the most popular source of PA for people with ID (McCarron et al. 2014). To date, no evidence exists on the impact of SOI participation on PA levels in Ireland.

4.2 Aim

To compare PA, physical fitness levels, BMI, and blood pressure of adults with ID, who do and do not take part in SOI programmes.

4.3 Objectives

- 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
- 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
- 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

4.4 Methodology

4.4.1 Procedures

Having consented to taking part in the study, 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 of a 20m flat indoor space for the Six Minute Walk Test. In order to ensure that participants were physically able to participate in the physical fitness walking test, all participants were required to complete a PA readiness questionnaire (PARQ). All participants met the criteria on the PARQ and were deemed ready to complete the submaximal walking test. A registered nurse was present for the collection of all physical data.

4.4.2 Measures

As there is no validated instrument available for collection of self-reported PA data for this population, the questionnaire used to ascertain the self-reported level of PA was an adapted version of the Survey on Lifestyle and Attitude to Nutrition (SLÁN-06, 2006). This is a survey on the lifestyle, attitudes and nutrition that has been used across the general population in Ireland (Conry et al. 2011). The questionnaire used in this study contained questions on i) demographics, ii) general health, and iii) PA levels with questions derived from the short form International PA Questionnaire (IPAQ). PA was defined as mild, moderate and vigorous. To help create a more user friendly questionnaire pictorial representations of various activities were added to the questionnaire. All questionnaires were administered face-to-face with 1:1 researcher to participant/family member. Individuals with an ID were given the opportunity to answer the questions posed themselves, with assistance from family members when required. The level of support required varied from individual to individual in this heterogeneous population.

In addition to the self-report PA data, we collected an objective measurement of PA by inviting participants to wear an Actigraph (GT3X) accelerometer over the right hip on an elasticized belt for 7 days directly following the data collection day. Participants were asked to wear the device at all times while awake and only to take it off while swimming/bathing or doing contact sports where the device could get damaged. Monitors were collected after the 7 days monitoring had been completed by study investigators, either at the home of participants or from their service provider. Data was recorded in 10 second epochs. Data was downloaded using ActiLife software (version 6.11.3).

The WHO STEPwise approach to Surveillance (STEPS) is a simple, standardized method for collecting, analysing and disseminating data in WHO member countries (WHO 2016). 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. 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. In line with established international practice for anthropometric measurements (WHO 2008), two consecutive weight and height measurements were taken and the average of the two measurements was recorded. Body Mass Index (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.

Participants also completed the Six-Minute Walk Test (6MWT), which is a widely accepted reliable and valid tool for measuring functional exercise capacity in people with disabilities (Nasuti, Stuart-Hill and Temple 2013, Casey et al. 2012, Waninge et al. 2011, Vis et al. 2009). 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 different studies using lengths ranging from 20-50m (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. Following guidelines outlined by the American Thoracic Society (2002) on conducting the 6MWT, a resting blood pressure measurement was taken prior to commencing the sub-maximal test. Participants were asked to remain seated for at least 15 minutes before the test began. After this time, we checked for contraindications; this included measuring pulse and blood pressure using the Omron I-Q142 model, and making sure that clothing and shoes were appropriate. Our protocol stated that any individuals who had a resting heart rate of >120bpm, or a systolic blood pressure of >180mm/Hg, or a diastolic blood pressure of >100mmHg, were deemed unsuitable for the test and would be advised by the nursing team to seek further advice from their medical GP. All other standardised testing procedures published by the American Thoracic Society were adhered to during data collection in this study, with some modifications including a 1:1 pacer and encouragement was given every 15 seconds. (validated by Nasuti, Stuart-Hill and Temple (2013) in a study with adults with ID). A 20 metre sports hall with a flat surface was used throughout the study. Larger cones were placed at the start and end point of each lane with smaller cones laid out every 2 metres. The lead researcher called out instructions, while a member of the research team accompanied each participant on the walk, with the pace being set by the individual participant.

4.4.3 Data Processing

Within the self-report questionnaire, participants reported how many days they completed tasks at light, moderate or vigorous intensities over the previous 7 days. They also reported how much time was spent doing each activity. From this, the average minutes spent doing light, moderate and vigorous activity reported per day was calculated by multiplying the number of days by the number of minutes and then by dividing by 7 days. MVPA was calculated by adding the moderate and vigorous activity scores together. Six minute walk test scores were calculated by adding up the total distance (in metres) covered by the participant within the six minutes, with the greater the distance covered indicating the greater fitness levels.

Accelerometer data was collected from 107 participants; however, a minimum of four valid days was required for inclusion in this study. 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 in sedentary, light, moderate and vigorous intensity PA were calculated using Freedson adult cut-points (Freedson, Melanson and Sirard 1998). 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 the participant wore the monitor for a minimum of 10 hours.

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 weight 18.5-24.99kg/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).

4.4.4 Data analysis

All data was 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 ANOVAs were used to investigate differences in MVPA accelerometer scores across the three age categories. A series of two-way between groups ANOVAs 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.

4.5 Results

Table 1 shows the mean ± SD of age and BMI of the total sample, and also of the breakdown by SOI and non-SOI participants.

Table 1: Descriptive statistics, mean (SD) age, BMI and health profile score

		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/m²)	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)

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, while 46.1% were considered moderate, and 6.4% were deemed severe (see Table 2). Information on gender, age, BMI and blood pressure of participants overall, and by SOI participation status are given in Table 1 above and Table 2 below.

Table 3 gives an overview of minutes of sedentary, light and MVPA (by accelerometry and self-report), percentage meeting the 30-minute MVPA guideline, 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.

When self-report minutes of MVPA were considered as can be seen in Table 3 below, again SOI participants 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, however, F (2, 117) = 10.19, p = .002 with a medium effect size (partial eta squared = .080), indicating that SOI participants accumulated significantly more minutes of MVPA daily than non-SOI participants. With regard to accelerometry data, SOI participants again recorded more 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 however; the interaction 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).

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). 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).

Table 2: Frequency table of study participants

	Total pop. (n)	%	SOI (n)	%	Non-SOI (n)	%
Gender						
Male	85	58.2	64	63.4	24	47.1
Female	61	41.8	37	36.6	27	52.9
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	49.2	45	49.5	13	48.1
Prehypertension	54	45.8	40	44	14	51.9
High BP Stage 1	2	1.7	2	2.2	0	0
High BP Stage 2	3	2.5	3	3.3	0	0
Hypertensive Crisis	1	0.8	1	1	0	0

Table 3: 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)

4.6 Discussion

The purpose of this study was to explore the PA habits and physical fitness levels of adults with ID, who do and do not take part in SOI. Participants in the current study spent most of their waking hours sedentary, accumulating a mean 679.5 ± 182.1 sedentary minutes per day. These findings are similar to previous research in relation to sedentary behaviour and people with ID (Philips and Holland 2011, Temple and Walkley 2003, 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. 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).

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 accumulating more mean minutes of MVPA per day than non-SOI, the large differences between accelerometer (50.9 ± 33.3 mins) and self-report (22.3 ± 30.6 mins) measured MVPA must be noted. The current study indicates that only 29.2% of the population reported sufficient MVPA minutes to meet >30mins MVPA guidelines. While no other Irish studies have been identified using similar methodologies for people with ID, for a representative sample of the general population, the SLÁN study used self-report as a means of gathering data on MVPA. Fifty five percent of the general population reported being ‘physically active’. This meant 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 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).

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. In the USA, 44 adults with an ID 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). However, there are limitations to the study including a small sample size. Similarly, Frey (2004) found that in a sample of 22 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 Actigraph model 7164 accelerometers with a representative sample of the general population. For adults and older adolescents, intensity thresholds were calculated as a weighted average of criteria determined from four studies that based criteria on treadmill or track walking. The resulting intensity-threshold criteria were 2020 counts for moderate intensity and 5999 counts for vigorous intensity. Findings revealed that adults were averaging 6-10 minutes MVPA per day across the age of 16-69 years.

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).

The low participation 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, are relevant and appropriate for this population. The high levels of activity found within this population sample may have also been influenced by the fact that people with severe ID were underrepresented in this study population, thereby potentially favouring a more active sample. Further research is needed to examine this issue before researchers can really get a true objective measure of PA for this group.

Given the low sample size in the non-SOI group whose accelerometer data fit the inclusion criteria (n= 19), and the subsequent impact on power, it is perhaps not surprising that no significant difference in MVPA level by accelerometer was found in the current study, despite the descriptives reporting higher accumulation in the SOI group overall. When we consider 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 indicates that a large number of participants (70.2%) did not report 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 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 (SLÁN 2007).

Physical fitness was measured using a modified sub maximal Six Minute Walking Test (6MWT). The mean distance covered in the current study was 518.5m ± 110.6, with SOI participants (541 ± 110.6) scoring significantly more metres (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 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 therefore not surprising that they scored higher distances than those with severe ID, COPD and heart failure participants. 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 for example; familiarisation sessions, pacers, level of encouragement and varying distances used, which may all have the potential to affect walking distance of study participants.

Familiarisation sessions have been recommended for people with an ID (Waninge et al. 2011, Rintala, McCubbib and Dunn 1995) with Casey, Wang and Osterling (2012) finding an increase in walking distance after 2 practice walks emphasising 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.

Consistent with previous research for people with ID, pacers and additional encouragement were used in the current study (Nasuti, Stuart-Hill and Temple 2013, Waninge et al. 2010, Beets, Pitetti and Fernhall 2005, Rintala, 1992). The use of 1:1 pacers adds to the staffing demand so future researchers may wish to examine the impact of removing pacers or increasing the participant-to-staff pacer ratio. In order to prevent affecting the distance walked, we followed the protocol of Waninge et al. (2010) 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 increase the amount of turns needed, 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. The current study used a 20 metre flat surface for logistical purposes. The authors of this study recommend the modified 6MWT as a straightforward and practical test with few time, space, measurement, and equipment requirements.

In relation to blood pressure (BP), only 4.2% of the participants in the current study had a blood pressure measurement in the hypertensive range. While acknowledging the limitation of single measurement, it is surprising that the majority of this population had blood pressure 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 ID (17.5%) 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 PA levels of individuals in the study. Previous research has shown that like the general population, PA can reduce BP for individuals with ID (Pett et al. 2013, Calders et al. 2011).

Of the study group, 86 people 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 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 (Walsh, Hall and

Ryan 2008). It is worthwhile noting that those in SOI (2.18 ± 0.81) had a significantly more positive health profile score (p=.013) than those not in SOI (1.64 ± 0.70).

International studies have looked to examine the effect of PA on different aspects of health in persons with ID (Escobar et al. 2013, Bartlo and Klein 2011, Rimmer et al. 2004) and have consistently shown a positive impact of PA participation in health and well-being. Pett et al. (2013) for example, 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 that took place twice per week (1.5 hours/session) for a total of 36 hours. Similar to the current study, compared with controls, at a 3 month follow up, the intervention group found improvements in BP, weight, and balance (p= .05). To the best knowledge of the authors, no other studies have been published investigating the impact of SOI participation on PA and fitness levels of individuals with ID either nationally or internationally, and so comparisons in that sense cannot be made.

4.7 Conclusions

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 PA levels than recommended for health, and have lower fitness levels than the general population. The findings in the study show that participants in SOI accumulate significantly more minutes of MVPA per day, have higher fitness levels, and more positive health profile scores than persons with ID that do not participate in SOI. As one of the most favoured forms of PA for people with ID in Ireland, these finding are very promising as they highlight the potential SOI has on making a difference to people’s physical health, and subsequently their overall health and well-being.

5. Report 3: SOPHIE (Special Olympics Programmes Health Impact Evaluation) Study: Nutrition intake and status.

5.1 Introduction

Persons with an ID are a nutritionally vulnerable group. They may have limited knowledge and understanding of nutrition and health, poor cooking skills, reduced abilities and opportunities to make informed nutritional choices, difficulties with transport to purchase food for themselves and reliance on others for nutritional adequacy and provision (British Dietetic Association 2011).

It is thought that people with ID are more likely to be overweight or obese than the general population. Different sample sizes, study populations, age ranges of participants and methodologies used in studies make it difficult to accurately quantify the issue of overweight and obesity in people with ID. The prevalence of overweight in people with ID is estimated between 28-38.2% and the prevalence of obesity is estimated between 25.6-51% (Hsieh et al. 2014, McCarron et al. 2014, de Winter et al. 2012a, Stedman and Leland 2010, Bhaumik et al. 2008, Emerson 2005, Yamaki 2005).

Being overweight is one of the five highest risk factors for disease burden in developed countries (WHO 2002). Obesity and overweight are some of the most preventable secondary conditions for individuals with disabilities (Rimmer et al. 2011). Obesity is associated with increased morbidity, cardiovascular disease, some cancers, type 2 diabetes, physical impairment, psychological issues (including distress and depression), reduced quality of life and economic burden (Finer 2015, Dixon 2010). It is estimated that through increased healthcare needs and indirect costs, such as absenteeism, obesity associated costs are €1,127,584,243 in the Republic of Ireland and €510,323,754 (£369,799,820) in Northern Ireland (Dee et al. 2012).

The WHO global disability action plan 2014-2021 identified that strengthening the collection of relevant and internationally comparable data on disability is a key priority (WHO 2014). Given the consequences of overweight and obesity and that they are potentially preventable, further research gaining insight into this issue in people with ID is important.

There does not appear to be any studies, with representative samples of the whole population of people with ID, which explain why individuals with ID are more likely to be overweight and obese than individuals without ID. In particular, there appears to be a gap in our knowledge of the nutritional intake of people with ID.

5.2 Aim

The aim of this part of the study is to describe the anthropometric status and the nutritional intake in people with ID.

5.3 Objectives

- To compare anthropometric (BMI and waist circumference) measures of people with ID who take part and do not take part in SO programmes.
- To compare nutrition intakes of people with ID who take part and do not take part in SO programmes and explore the factors influencing these.

5.4 Data Collection Methods

5.4.1 Dietary Intake

There is currently no validated method for collecting data on the nutritional intake of people with ID. Food diaries require the respondent to record a detailed description of food and drink items consumed, and the time of consumption, for an agreed period of time. Estimated food diaries require respondents to estimate portion sizes, often using household measures, whereas weighed food diaries are the most accurate, requiring respondents to weigh all items consumed (Gibson 2005). Recording periods of 7 days are considered the most accurate for estimating usual dietary intake but places a high burden on the respondent, therefore periods ranging from 2 to 5 days are often used (Gibson 2005). Given the challenges in collecting dietary data in this population and the need for proxy reporting in various locations, it was decided that a 4 day estimated food diary, including 2 weekend days, was the most appropriate dietary assessment tool to gather detailed contextual and nutritional intake data in study participants.

Permission was obtained to adapt the ROOTS 4 day food diary (University of Cambridge 2016).

A video of instructions was developed and participants were given a copy of this on request. Written instructions were developed and included at the beginning of food diaries. Verbal instructions were also provided at the time of the research interview and on-going support by telephone was offered to all participants.

Given the complexity of completing food diaries, family members or service provider staff acted as proxy reporters. Reporters were requested to estimate portion sizes using household measurements such as measuring cups, spoons, or glasses, or by calculating weight or volume as indicated on packaging labels. Portion sizes not clearly recorded were estimated using Food Portion Sizes (Lyons and Giltinan 2013). Reporters were encouraged to contact the researcher if they had difficulties completing food diaries. Where possible the researcher, a registered dietitian, collected and reviewed food diaries for errors face-to-face with reporters. If this was not possible, food diaries were posted and on review if errors were identified the researcher contacted reporters via telephone. In addition to the food diary, a column capturing contextual information on the source and location of all food consumed was included.

5.4.2 Anthropometric Data

"The WHO STEPwise approach to Surveillance (STEPS) is a simple, standardized method for collecting, analysing and disseminating data in WHO member countries" (WHO 2016). 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. ?Q q?

Height (m) and weight (kg) were measured to the nearest 0.1m and 0.1kg, respectively, using a stadiometer (Leicester Height Measure) and calibrated digital weighing scales (TANITA HD-305 and TANITA WB-100MA). 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 midpoint between the lower margin of the last palpable rib and the top of the iliac crest (hip bone) at the end of a gentle expiration, with participants' arms relaxed at their sides. Waist circumference measurements were taken behind a 3 sided portable screen to allow participants privacy.

5.5 Data Handling and Analysis

5.5.1 Data Storage

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.

5.5.2 Data Entry and Cleaning

Questionnaire data was entered into Microsoft Excel. When all relevant data was entered each record was manually checked for errors by a team of two researchers. Data cleaning was carried out in SPSS. Food diary data was entered into the nutritional analysis software WISP (Version 4.0, Weighed Intake Software Package; Tinuviel Software, Warrington, UK). When all relevant data was entered each record was manually checked for errors and amended where required. The analysis was exported to Microsoft Excel and SPSS.

5.5.3 Data Processing

To facilitate analysis, ID diagnosis was recoded into a new variable of interest: diagnosis of Down syndrome and ID diagnosis of other aetiology. Living arrangements were recoded to living at home (family home) or not. Participants were divided into three groups according to their age, in similar groups as the 2007 SLÁN study (Harrington et al. 2008), 16-29.9 years, 30-44.9 years and 45-64.9 years. This allowed for comparison with a nationally representative Irish sample. Data collected in 2006-2007 on anthropometric measurements and nutritional intakes in the general Irish population will be used for comparison with study participants throughout this study (Harrington et al. 2008).

BMI was classified using WHO (1995) classifications as follows: underweight: BMI<18.5kg/m^2, normal weight: BMI 18.5-24.9kg/m^2, overweight: BMI 25-29.9kg/m^2, obese: BMI ≥30kg/m^2. WHO (2011) waist circumference cut-off points for risk of metabolic complications were used; waist circumference >94 cm for men and >80 cm for women indicating increased risk and waist circumference >102 cm for men and >88 cm for women indicating substantially increased risk.

Nutrients of interest in the Irish population for the discussion chapter of this report were identified from the Scientific Recommendations for Healthy Eating Guidelines in Ireland (Food Safety Authority of Ireland 2011) and include energy, % energy from fat, % energy from saturated fat, % energy from sugar, fibre, iron, calcium and vitamin D. Data is available for the general Irish population intake of energy, % energy from fat, fibre, iron, calcium and vitamin D (Harrington et al. 2008). Recommendations for intake of nutrients were obtained from the Food Safety Authority of Ireland (2011, 2005, 1999) and the UK Department of Health (1991).

5.6 Data Analysis

Data was analysed using IBM SPSS Statistics 22.0. Missing data was coded as 999. A significance level at a *P* value of .05 was used for all analyses. 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, percentages, medians and percentiles, where appropriate. Independent sample t-tests were used to examine the difference between means. One-way between groups ANOVAs were used to investigate differences between anthropometric measurements of those who do and do not take part in SOI. Chi-square analysis and Fisher's exact test were used to examine differences to contextual dietary intake questions between those who do and do not take part in SOI and by level of ID and if there were any differences between contextual information around food and BMI classification. This was repeated for those who do and do not take part in SOI. To explore associations between BMI and waist circumference with age, gender, level of ID, diagnosis of Down syndrome or other ID, living at home or not and participation in SOI univariate analysis was used (independent variables entered individually). Significant variables were then entered into a multivariate (independent variables entered simultaneously) linear regression analyses. A series of two-way between groups analyses of variance were conducted to explore the impact of SOI participation and gender on nutrient intakes.

5.7 Results

5.7.1 Response Rates

131 people (86 athletes and 45 non-athletes) with ID participated in this element of the study (see table 1).

Table 1 showing the characteristics of the sample and participation rates for the anthropometry and food diary elements.

	Total Sample		Completed Anthropometry		Completed Food Diary	
	n	**%**	**n**	**%**	**n**	**%**
Gender						
Male	77	59	71	58	49	57
Female	54	41	52	42	37	43
Age Category (years)						
16-29	57	44	54	44	41	48
30-44	48	37	44	36	27	31
45-64	26	20	25	20	18	21
Level of ID						
Mild	60	48	56	48	39	47
Moderate	60	48	58	49	39	47
Severe	6	5	4	3	5	6
ID Diagnosis						
Down Syndrome	56	44	55	46	42	49
Cerebral Palsy	7	6	5	4	4	5
Autism	14	11	13	11	8	9
Non specific ID	31	24	29	24	19	22
Other	19	15	17	14	12	14
Living Arrangements						
Living at home	105	80	98	80	75	87
5 day community group home	1	1	1	1		
7 day community group home	6	5	6	5	3	4
5 day residential centre	7	5	7	6	5	6
7 day residential centre	6	5	5	4	2	2
Other	6	6	6	6	1	1
Geographical Location						
In open country	39	30	39	32	28	33
In a village	20	16	17	14	12	14
In a town (1,500 +)	13	10	11	9	7	8
In a city (other than Dublin)	22	17	21	17	12	14
In Dublin	35	27	33	27	26	31
Member of SOI						

Yes	86	66	84	68	60	70
No	45	34	39	32	26	30
BMI Categories						
Underweight	3	2	3	2	3	4
Normal Weight	28	23	28	23	21	25
Overweight	35	28	35	29	24	29
Obese	58	47	57	46	35	42

* Because of rounding errors some percentages may add up to slightly more or less than 100%.

5.7.2 Anthropometric Measurements

Table 2 describes the mean, SD and range of the anthropometric measurements collected in this study for the total sample and those who do and do not take part in SOI. The mean BMI of the overall study sample was 29.4(±6.1)kg/m^2. The mean waist circumference of the overall sample was 93.3cm. There was no significant difference identified between any of the anthropometric measurements obtained for those who do and do not take part in SOI.

Table 2: Distribution of anthropometric measurements obtained for the total sample and those who do and do not take part in SOI

		Mean	Std. Deviation	Minimum	Maximum
Total	Height (m)	1.60	0.13	1.28	1.99
	Weight (kg)	74.8	19.0	32.1	124.7
	BMI (kg/m^2)	29.4	6.1	16.3	47.9
	Waist (cm)	93.3	14.8	64.0	130.0
In SOI	Height (m)	1.60	0.14	1.28	1.99
	Weight (kg)	75.1	19.0	46.1	124.3
	BMI (kg/m^2)	29.4	6.1	16.8	43.7
	Waist (cm)	92.2	14.7	64.0	129.0
Not in SOI	Height (m)	1.59	0.13	1.39	1.89
	Weight (kg)	74.4	19.2	32.1	124.7
	BMI (kg/m^2)	29.4	6.2	16.3	47.9
	Waist (cm)	96.0	15.0	71.0	130.0

5.7.3 Distribution of BMI

BMI classification (World Health Organisation 1995) categorises 2.4% of the sample as underweight, 22.6% as normal weight, 28.2% as overweight and 46.8% as obese. Worryingly, 75% of the sample is overweight or obese. Table 3 describes the distribution of BMI by gender, age category, level of ID, diagnosis, living arrangement and SOI participation which previous research suggests may be associated with BMI.

Table 3: Distribution of BMI (kg/m^2) by gender, age category, level of ID, diagnosis, living arrangement and SOI participation

	Mean	Median	25th Percentile	75th Percentile
Gender				
Male	**28.8**	**28.4**	**24.8**	**33.5**
Female	**30.1**	**30.1**	**24.9**	**34.8**
Age Category (years)				
16-29	**28.1**	**26.9**	**23.4**	**33.8**
30-44	**31.1**	**31**	**26.2**	**34.8**
45-64	**29.3**	**28.4**	**25.8**	**33.7**
Level of ID				
Mild	**28.6**	**27.1**	**24.7**	**34**
Moderate	**30.4**	**30.8**	**25.6**	**33.9**
Severe	**22.9**	**19.6**	**16.4**	**32.6**
ID Diagnosis				
Down Syndrome	**31**	**30.7**	**26**	**35.7**
ID Other Aetiology	**27.7**	**27.1**	**24.1**	**31.7**
Living Arrangements				
Living at home	**28.9**	**28.8**	**24.5**	**33.8**
Not living at home	**31.1**	**30.9**	**25.9**	**36.3**
Member of SOI				
Yes	**29.4**	**29.1**	**24.7**	**34.3**
No	**29.4**	**29.1**	**25.6**	**33.7**

The mean BMI of those who take part in SOI was 28.9kg/m^2 for men and 30.2 kg/m^{2}for women. The mean BMI of those who do not take part in SOI for men was 28.5kg/m^2 and for women was 30.1 kg/m^2. There was no significant association between SOI participation and BMI (p=0.948).

5.7.4 Associations with BMI

Results of univariate linear regression are displayed in table 4. Independent variables included in the model were age, gender, level of ID, diagnosis of Down syndrome or other ID, living at home or not and participation in SOI. Univariate analysis identified a significant association between a diagnosis of Down syndrome with BMI. R^2= 0.075, therefore 7.5% of the variance is explained by a diagnosis of Down syndrome.

Table 4: Linear Regression Analysis with BMI

	Univariate Regression			
	B	**Sig.**	**95% CI**	
Age	0.08	0.122	-0.20	0.18
Gender	1.37	0.223	-4.42	3.58
Level of ID	0.31	0.753	-3.83	2.22
Diagnosis of Down Syndrome	-3.36	0.003	-4.31	-1.20
Living at home or not	2.46	0.075	-0.25	5.17
Participation in SOI	0.08	0.948	-2.23	2.38

Note: B represents unstandardized regression co-efficient

5.7.5 Distribution of Waist Circumference

Table 5 describes the distribution of waist circumference by gender, age category, level of ID, diagnosis, living arrangement and SOI participation which previous research suggests may be associated with BMI.

The mean waist circumference of those who take part in SOI for men was 94.9cm and for women was 87.1cm. The mean waist circumference of those who do take part in SOI for men was 98.2cm and for women was 94.4cm. The waist circumference of those taking part in SOI is lower than those who do not, however this is not significant (p=0.196).

Table 5: Distribution of waist circumference (cm) by gender, age category, level of ID, diagnosis, living arrangement and SOI participation

	Mean	**Median**	**25th Percentile**	**75th Percentile**
Gender				
Male	90.6	95.5	82.4	106.5
Female	90.1	89	78.5	97.4
Age Category (years)				
16-29	89.5	87	78	98
30-44	95.8	95	84	106
45-64	97	100	88.5	106.6
Level of ID				
Mild	90.4	89	80.5	99.1
Moderate	95.9	95	82.8	106.5
Severe	98.4	98.4	77	
ID Diagnosis				
Down Syndrome	92.4	93	81	101
ID Other Aetiology	92.8	89.8	81.5	102
Living Arrangements				
Living at home	92.8	92	79.9	102
Not living at home	95.8	96	87.7	102.3
Member of SOI				
Yes	92.2	92	80.5	102

No	96	95	87	107

5.7.6 Association with Waist Circumference

Results of univariate and multivariate linear regression are displayed in table 6. Independent variables included in the model were age, gender, severity of ID, diagnosis of Down syndrome or other cause of ID, living at home or not and participation in SOI. Univariate analysis identified a significant association between waist circumference and increasing age, being male and increasing severity of ID. These variables were entered into a multivariate analysis model, which identified a significant association between waist circumference and increasing severity of ID. The association between increasing age (p=0.053) and being male (p=0.06) and increasing waist circumference was almost significant. R^2= 0.102, therefore 10% of the variance is explained by the multivariate model.

Table 6: Linear Regression Analysis with Waist Circumference

	Univariate				**Multivariate**			
	B	**Sig.**	**95% CI**		**B**	**Sig.**	**95% CI**	
Age	0.26	.039	0.01	0.50	0.178	0.053	-0.004	0.49
Gender	-5.54	.045	-10.96	-0.12	-0.173	0.06	-10.59	0.21
Level of ID	4.86	.041	0.20	9.53	0.188	0.04	0.212	9.31
Diagnosis of Down Syndrome	0.50	.858	-5.06	6.07				
Living at home or not	2.90	.399	-3.89	9.68				
Participation in SOI	3.72	.196	-1.95	9.39				

Note: B represents unstandardized regression co-efficient

5.7.7 Health Promotion Programme and Anthropometric Measurements

Of those who take part in SOI, 14.9% reported they had participated in the SO Health Promotion Programme, 73.6% had not and 11.5% did not know if they had participated or not. No l effect on BMI or waist circumference was detected in those who did report taking part.

5.7.8 Contextual Anthropometric Data from Questionnaires

41% of study participants said they were ‘about the right weight’, 33.6% said they were ‘too heavy’, 8.4% said they were ‘too light’ and 16.8% said they were ‘not sure’.

When asked ‘are you actively trying to manage your weight?’ 48.9% of study participants said yes and 51.1% said no.

When asked ‘in the past 12 months has a doctor, nurse or other health professional advised you to lose, maintain, or gain weight?’ 18.8% of participants reported ‘yes, lose weight’, 3.1% reported ‘yes, maintain current weight’, 1.6% reported ‘yes, gain weight’ and 76.6% reported ‘no’.

5.7.9 Contextual Nutritional Intake Data from Questionnaires

Table 7 shows the distribution of answers relating to food choices, food preparation, cooking skills level and autonomy of those who do and do not take part in SOI. Differences between those in and not in SOI and by level of ID were analysed. Those in SOI were more likely to cook alone or with support (p = 0.05). There was no significant difference by level of ID (p=0.63). Those in SOI were more likely to shop alone or with support (p = 0.05). There was no significant difference by level of ID (p=0.49). Those with a mild ID were more likely to make their own food choices (p=0.05) and have better cooking skills (p=0.001).

The association between contextual nutritional intake data from questionnaires and BMI categories was also examined separately for those who do and do not take part in SOI, with no significant associations identified using Chi-square tests.

Table 7: Distribution of answers relating to food choices, food preparation, cooking skills level and autonomy of those who do and do not take part in SOI

Do you make your own food choices?	Always	Usually	Sometimes	Rarely	Never
Athletes (%)	14	16	44	14	12
Non-athletes (%)	11	11	48	11	18
When you do not, who makes your food choices?	Family member	Paid Care Worker	Other		
Athletes (%)	81	8	11		
Non-athletes (%)	60	36	4		
Who prepares your meals?	Yourself without support	Yourself with support	Family member	Paid Care Worker	Friend
Athletes (%)	12	11	65	11	1
Non-athletes (%)	5	7	57	32	0
Who usually cooks your meals?	Yourself without support	Yourself with support	Family member	Paid Care Worker	Friend
Athletes (%)	6	6	72	13	1
Non-athletes (%)	2	7	56	33	0
Describe your cooking skills?	Poor	Fair	Average	Good	Very good
Athletes (%)	31	21	12	29	7
Non-athletes (%)	58	14	7	16	5
Who does your food shopping?	Yourself without support	yourself with support	Family member	Paid Care Worker	Friend
Athletes (%)	4	15	69	11	1
Non-athletes (%)	0	14	56	31	0
Do you plan foods bought for you?’	Always	Usually	Sometimes	Rarely	Never
Athletes (%)	12	15	35	26	13
Non-athletes (%)	7	16	31	9	38
Did you eat snacks yesterday?	Yes	No			
Athletes (%)	76	24			
Non-athletes (%)	78	22			
Number of snacks	1	2	3	4	>5
Athletes (%)	45	27	13	5	11
Non-athletes (%)	41	44	6	6	3

5.7.10 Nutritional Intake

The nutritional intake of those who do and do not take part in SOI is described in table 8. Comparisons are made with recommended intakes.

The mean nutrient intake of those who do and do not take part in SOI and by gender were examined. Intakes of energy, protein, fat, % energy from fat, % energy from saturated fat, sugar, % energy from sugar, fibre, sodium, vitamin C, vitamin D, iron and calcium were analysed. There were no statistically significant differences between those who do and do not take part in SOI. Males' intake of energy (p=0.001), protein (p=0.012), fat (p<0.001), % energy from fat (p=0.003), % energy from saturated fat (p=0.005), sodium (p=0.001) and iron (p=0.005) were significantly higher than females' intake.

Table 8: Distribution of mean nutrient intake of those who do and do not take part in SOI in comparison with recommended intakes

Nutrient	Mean	Std. Dev.	Minimum	Maximum	Rec.
Energy (kcal)	1889.5	467.0	832.0	3028	2200 (1800)[a]
Protein (g)	77.5	18.7	41.9	142.6	55.5 (45) [b]
Carbohydrate (g)	230.4	63.4	89.4	439.0	
Energy from Sugar	22.6%	7.2%	9.4%	22.6%	≤10% [a]
Total Fat (g)	79.0	26.7	27.6	141.0	
Energy from Fat	37.1%	5.8%	21.7%	37.1%	20-35% [a]
Saturates (g)	34.0	13.6	9.5	68.5	
Energy from Sat Fat	15.9%	3.7%	6.1%	15.9%	≤10% [a]
Monounsaturates (g)	24.2	9.0	7.3	47.8	
Polyunsaturates (g)	11.1	5.4	3.3	29.5	
Fibre (g)	17.8	6.6	5.5	44.9	≥25[a]
Sodium (g)	2.7	9.4	0.1	7	1.6[c]
Calcium (mg)	927.8	340.3	337.0	2172	1000[d]
Iron (mg)	10.8	3.4	4.5	25.01	10 (14)[d]
Vitamin D (µg)	2.2	1.5	0.4	9.39	5[d]
Folate (µg)	284.2	108.4	147.0	713	300[d]
Vitamin C (mg)	150.7	166.4	17.0	1157	60[d]
Vitamin B12 (mg)	4.8	2.4	1.2	14.8	1.4[d]

*Recommended amounts per day, unless given in other terms. If that for women is different from that for men, it is given in parenthesis. Where there was a range the mean value was used for comparison.

[a] Recommendations are goals from the Food Safety Authority of Ireland (2011)

[b] Recommendations are RNI from the UK Dept. of Health (1991)

[c] Recommendations are RDA from Food Safety Authority of Ireland (2005)

[d] Recommendations are RDA from Food Safety Authority of Ireland (1999)

The mean nutrient intake of those who do and do not take part in SOI and by gender were examined. Intakes of energy, protein, fat, % energy from fat, % energy from saturated fat, sugar, % energy from sugar, fibre, sodium, vitamin C, vitamin D, iron and calcium were analysed. There were no statistically significant differences between those who do and do not take part in SOI. Males' intake of energy ($p=0.001$), protein ($p=0.012$), fat ($p<0.001$), % energy from fat ($p=0.003$), % energy from saturated fat ($p=0.005$), sodium ($p=0.001$) and iron ($p=0.005$) were significantly higher than females' intake.

5.8 Discussion

The results of this study highlight the alarming prevalence of obesity in people with ID. In a representative sample of the general population 2% are underweight, 38% are normal weight, 38% are overweight and 23% are obese. While less of the current sample of people with ID are overweight (28.2%) compared to the general population, worryingly the prevalence of obesity is double (46.8%). The prevalence of obesity in the study sample is broadly consistent with previous studies (Hsieh et al. 2014, Bhaumik et al. 2008, McGuire, Daly and Smyth 2007, Emerson 2005, Yamaki 2005). In an Irish sample of older people with ID (over 40 years of age) who had height and weight directly measured, 34.8% of the sample was overweight and 42.5% were obese (Arvidsson and Jonsson 2006). The prevalence of overweight and obesity, at 77.3%, is similar to that of this study.

Individuals with a diagnosis of Down syndrome were at increased risk of obesity compared to other people with ID. This has been found in previous studies (Hsieh et al. 2014, Melville et al. 2005). Previous studies have also identified an association between obesity and being female (Hsieh et al. 2014, Emerson 2005), increasing age (de Winter et al. 2012a, Emerson 2005), having a less severe ID (de Winter et al. 2012a, Stancliffe et al. 2011) and taking medications that can cause weight gain (de Winter et al. 2012a, Hsieh et al. 2014). Association between these variables and BMI were not significant in the study sample.

Increased waist circumference measurements were significantly associated with increasing severity of ID in the study participants. Using waist circumference cut offs (WHO 2011) 36.2% of men and 55.1% women are at substantially increased risk of metabolic complications. In previous research in people with ID, BMI measurements are typically taken over waist circumference. De Winter et al. (2012b) obtained waist circumference measurements and reported that in a Dutch sample of older people with ID 24% of men and 64.3% of women had a waist circumference that classifies them as being at substantially increased risk of metabolic complications. These results are lower than men in the current sample but higher for women.

The mean waist circumference of those taking part in SOI was lower than those not taking part in SOI, however this difference was not significant (p=0.196). Waist circumference was lower in the sample of people with ID than in the general population, 95.6cm compared to 99.5cm for men and 90.1cm compared to 90.5cm for women.

It is alarming that given that 75% of the study sample are overweight or obese only 33.6% said they were ‘too heavy’ and 76.6% reported that no doctor, nurse or other health professional had advised them to lose, maintain, or gain weight. This is surprising given the major issue of overweight and obesity in this population. There is currently no national Irish policy relating to nutrition in people with ID. The National Taskforce on Obesity (2005), as part of the Framework for Obesity Prevention, stated that ‘the health services should recognise maintenance of a healthy weight as an important health issue, and measurement of height, weight, waist circumference and calculation of BMI should be part of routine clinical healthcare practice in primary care and in hospitals’. There is certainly room for improvement in the implementation of this policy in this population.

Almost half of participants reported that they are actively trying to manage their weight. Given the prevalence of overweight and obesity in this population, improved service and support for those actively trying to manage their weight appears indicated. Successful strategies will need to take into account contextual information such as who chooses, prepares meals etc. given that 22% of participants never plan what is bought for them and 45% only ‘sometimes’ choose what foods they eat.

Given that those with a severe ID are under-represented and level of ID may be linked with BMI, it’s possible that the true prevalence of underweight is higher and overweight and obesity is lower than reported in this study.

Those in SOI were more likely to cook alone or with support ($p = 0.05$) and were more likely to shop alone or with support ($p = 0.05$). There was no significant association between level of ID and these abilities. This suggests that SOI participation may be associated with greater independence in cooking and shopping for people with ID. The cause of this is unknown but may include greater independence, participating in SOI events or greater self-concept from participating in SO (Weiss and Bebko 2008, Duvdevany 2002).

There was no significant impact on contextual dietary information on BMI classification, for those who do and do not take part in SOI. Previous studies have identified a possible link between contextual factors such as preparing foods independently, eating independently, grocery shopping independently, fizzy drink consumption and increased risk of being overweight or obese in people with ID (Hsieh et al. 2014, de Winter et al. 2012a, Bhaumik et al. 2008). The small, under-representative nature of this sample may explain why similar findings were not present.

There has been little comprehensive research into the dietary intake of people with ID. Comparisons with other studies are difficult, given different methodologies used. Comparisons with two Irish studies (McCarron et al. 2014, McGuire, Daly and Smyth 2007) are limited as they used a Likert scale of how often food items are consumed. No studies were identified using comprehensive dietary assessment methods, such as food diaries, in this population. Comparisons can be made, however, with recommended nutrient intakes. Limited comparisons can also be made with the general population (Harrington et al. 2008).

While there does appear to be under reporting in the food diaries completed, the data does highlight the poor diet quality of this sample of people with ID. Very few study participants are meeting micronutrient RDAs and the energy contributed from fat, saturated fat and sugar is greater than recommended in most study participants.

The mean reported energy intake of study participants was 2044kcal/day for men and 1684kcal/day for women, less than that reported in the general population at 2384kcal/day for men and 2173kcal/day for women. Reported mean energy intakes are lower for men and women than recommended energy intakes, 2200kcal/day and 1800kcal/day respectively. Recommendations for inactive males and females aged 19-50 years were used for comparison.

The mean percentage energy from fat was 39% for men and 34.7% for women, with 36% of participants meeting recommendations of ≤35% energy from fat. Draheim et al. (2007) reported a similarly high prevalence of high fat diets, 70.1-86.6% of participants had ≥30% energy from fat. Men’s intake in the general population (36%) was lower than male study participants. Women’s intake in the general population (35%) was similar to female study participants.

Just 5.8% of study participants met the recommendations of ≤10% energy from saturated fat. The mean percentage energy from saturated fat was 16.9% for men and 14.6% for women. Just 2.3% of study participants met the recommendations of ≤10% energy from sugar. The mean percentage energy from sugar was 21.7% for men and 23.8% for women.

Study participants’ mean iron intake per day was 10.8g. Male study participants’ mean intake exceeded the RDA; however, female study participants’ mean intake was lower than the RDA for women. Mean iron intakes were lower in the study population than the general population, 11.7mg/day compared to 13.5mg/day for men and 9.5mg/day compared to 13.2mg/day for women. More men than women met iron RDAs, 65.3% compared to 40.5%, respectively.

Study participants’ mean fibre intake per day was 10.8g. Just 10.5% of study participants consumed the recommended 25g/day. Mean fibre intakes were lower in the study population than the general population, 18.8mg/day compared to 26.4mg/day for men and 16.7mg/day compared to 26.9mg/day for women.

Study participants’ mean calcium intake per day was 928mg. The RDA for calcium was met by 35.9% of study participants. Mean calcium intakes were lower in the study population than the general population, 980mg/day compared to 1041mg/day for men and 859mg/day compared to 906mg/day for women.

Study participants’ mean vitamin D intake per day was 2.2 µg. Worryingly, just 3.5% of study participants met the vitamin D RDA. Mean vitamin D intakes were lower in the study population than the general population, 2.5µg/day compared to 3.8µg/day for men and 2.5µg compared to 3.5µg/day for women.

5.9 Limitations

Given that 75% of the sample was overweight or obese and no significant correlation was found between energy intake and anthropometric measurements, there appears to almost certainly be under reporting of nutritional intake in food diaries. One possible cause may be that proxy reporters are likely present for main meals but it’s possible that proxy reporters aren’t always present for snacks consumed, which may account for some of the under-reporting observed. Snack foods are often high in energy, fat and sugars but low in nutritive value. Therefore the energy, fat and sugar content of the sample diets may be higher than reported.

The method used to quantify the dietary intake of the general population was through a Food Frequency Questionnaire (FFQ). FFQs aim to estimate the frequency at which foods or food groups are consumed, with a list of foods and frequency-of-use response categories (Gibson 2005). FFQs are not as comprehensive as food diaries, therefore, the comparisons with the general population must be interpreted with caution.

The sample recruited to this study was lower than planned. Difficulties in recruitment in the population of people with ID have been documented. Lennox et al. (2005) reported an uptake of people with ID of 26.5%. Barriers to recruitment were identified including heavy ID staff caseloads, high demands and burdens of care faced by family members with non-essential tasks such as taking part in research a low priority, ethical constraints on directly approaching potential study participants and suspicion towards researchers from ID staff.

Nicholson et al. (2013) identified barriers to recruitment in people with ID, including difficulties for potential participants in understanding the future benefits of research, concerns about being able to answer questions, lack of interest and the influence of family and carer attitudes on people with ID.

The sample recruited in this study is not representative of the population of people with ID in Ireland. For example, those with a severe ID are underrepresented. Few studies exist examining the anthropometric and nutritional status of people with ID in Ireland. The findings may not represent the overall population but highlight the alarming prevalence of obesity and poor diet quality in this sample of people with ID.

5.10 Conclusions

- There was no significant difference identified between any of the anthropometric measurements obtained for those who do and do not take part in SOI.
- 2.4% of the sample is underweight, 22.6% are normal weight, 28.2% are overweight and 46.8% are obese. Worryingly, 75% of the sample is overweight or obese.
- The mean BMI of those who take part in SOI was 28.9kg/m^2 for men and 30.2kg/m^2 for women.
- The mean BMI of those who do not take part in SOI was 28.5kg/m^2 for men and 30.1kg/m^2 for women.
- Obesity is twice as prevalent in the study participants compared to the general population (47% compared to 23%).
- Having a diagnosis of Down syndrome is associated with increased BMI.
- Of those who take part in SOI, 14.9% reported they had participated in the SO Health Promotion Programme, 73.6% had not and 11.5% did not know if they had participated or not. There was no significant correlation with whether they had participated or not with BMI (r=-0.112, p=0.308).
- The mean waist circumference of those who take part in SOI was 94.9cm for men and 87.1cm for women. The mean waist circumference for those who do take part in SOI was 98.2cm for men and 94.4cm for women.
- Increasing severity of ID is significantly associated with increased waist circumference.
- Increasing age and being male are associated with increased waist circumference, but this is not statistically significant.
- Using waist circumference measurements 36.2% of men and 55.1% women are at substantially increased risk of metabolic complications.
- Those in SOI were more likely to cook alone or with support ($p = 0.05$) and were more likely to shop alone or with support ($p = 0.05$). There was no significant association between level of ID and these abilities.
- There were no statistically significant differences between the nutritional intakes of those who do and do not take part in SOI.
- The average energy intake reported was 2044 kcal/day for men and 1684 kcal/day for women; however, 75% of study participants were overweight or obese. Underreporting is suspected.
- Many study participants did not meet micronutrient RDAs.

6. Report 4: SOPHIE (Special Olympics Programmes Health Impact Evaluation) Study: Qualitative findings from focus group interviews and questionnaires with athletes, non-athletes, family and staff members.

6.1 Introduction

The SOPHIE study investigated the health and wellness of people with intellectual disability (ID), who are involved and not involved in SO. The aims were to investigate and assess over a near two-year period, the impact and contribution of the programmes of SOI to the health and well-being of persons with an ID on the island of Ireland, and also to assist SOI in developing a deeper understanding of key levers for change within its programmes. This study involved both quantitative and qualitative methods, and this report deals with the main qualitative element of the study.

SO is an international organisation which provides both sporting and social outlets for individuals with ID (Harada et al. 2011). It has been identified as being the most popular organisation or club that older Irish adults with ID attend (McCarron et al., 2014), with benefits for all age groups involved (Harada et al. 2011). Sports were found to be the most popular recreational activities for adolescents with ID, with nearly 40% of participants involved in at least one sport through SO (Abells, Burbidge and Minnes 2008). It has also been suggested that involvement in SO is positively connected with changes in a person's self-worth and perceived physical competence (Weiss and Bebko, 2008). Seeking to support people in thinking positively about themselves should be a goal for all concerned with supporting people with ID (Pestana 2105), as emotional well-being impacts on overall health. Policies such as *Valuing People* (DOH 2001) in the UK, and *New Directions* (Kinsella 2012) in the Republic of Ireland, identify quality of life issues such as health and well-being of people with ID as being of concern and therefore worthy of investigation.

No previous comprehensive mixed methods research studies have been conducted in Ireland to examine the impact of SO involvement in people with ID. People with ID struggle to maintain a healthy weight (Salaun and Berthouze - Aranda, 2012, Stewart et al. 2009) and obesity is a significant issue (George et al. 2011). This is also the case for individuals who participate in SO, with a higher reported prevalence of weight problems amongst female athletes (Temple, Foley and Lloyd 2014). Research supports the need to increase levels of physical activity, so that people with ID can share the physical health benefits, and also the psycho-social well-being improvements, of regular exercise (Dowling et al. 2012a).

The most significant facilitator to participation in any kind of physical activity appears to be associated with increasing social contact and networks. Being involved in a sporting club (which provides the opportunity to socialise with peers and be involved in a team), is a key aspect of participation regarded positively amongst individuals with ID (Barr and Shields 2011, Downs et al. 2013, Mahy et al. 2010, Temple and Walkley 2007).

Another factor found to facilitate participation is the opportunity to achieve, such as winning a medal or taking part in competitions (Mahy et al. 2010, Temple and Walkley 2007). Finally, structured programmes have been found to be a facilitator, regardless of whether they are run for non-disabled athletes or otherwise (Barr and Shields 2011).

For families and parents in particular, concerns can be identified regarding the responsibilities associated with caring for a person with ID, resulting in a lower sense of personal development and directedness in their lives (Walden, Pistrang and Joyce 2000), and higher levels of stress (Browne and Bramston 1998). Social opportunities for family members are often limited because of caregiving duties (Caples and Sweeney 2011), or restricted to socialising with other carers rather than their peers or partners (Yoong and Koritsas 2012). There is evidence of a beneficial relationship between families of athletes and SO, with aspects of involvement providing a supportive role for family members (Weiss and Bebko 2008), reducing stress while offering opportunities for parents to have positive experiences with their child (Weiss and Diamond 2005), and helping strengthen family relationships (Kersh and Siperstein 2012).

While being involved in SO may have benefits for families and athletes, there can be practical implications that may result in barriers to participation. Transport difficulties, the availability of family or staff members to provide support, and financial constraints, have been reported widely as barriers to participation in physical activity (Downs et al. 2013, Bartlo and Klein 2011, Mahy et al. 2010, Temple and Walkley 2007, Messent et al. 1999,). A lack of knowledge surrounding suitable opportunities to partake in physical activity has also been identified as a barrier to participation for people with ID (Downs et al. 2013, Temple and Walkley 2007). Staff working with individuals with ID on a daily basis may not understand what is needed regarding physical activity, and staff qualified in the area of physical activity often lack knowledge about working with people with ID (Temple and Walkley 2007). Other barriers can be a lack of motivation or desire to partake in physical activity (Downs et al. 2013, Temple and Walkley 2007), poor health or motor skills, and a lack of mainstream programmes (Barr and Shields 2011).

This qualitative study examines the experiences and views of people with intellectual disability, their families, and staff who work with them, about SO on the island of Ireland.

6.2 Method

The method involved focus groups with people with intellectual disability, their family or carers who were involved and not involved in SOI, conducting individual interviews with staff working in services for people with intellectual disability, and recording responses from qualitative questions included within the main study questionnaires. A breakdown of all sources of qualitative data is summarised in Table 1 below. The qualitative data reported here was collected within the Republic of Ireland only, while other elements of the study relate to the whole island of Ireland. Qualitative data was collected via focus group interviews with athletes, non-athletes and family members, while staff members were interviewed individually. Focus group interviews were the chosen data collection tool for individuals with ID and family members. For people with ID in particular, who could otherwise be excluded from the research process (Barr and Shields 2011), focus groups were identified as a suitable method. Focus groups were used effectively with people with ID in studies that sought to seek their views and experiences of advocacy (Llewellyn and Northway 2008), barriers to social inclusion (Abbott and McConkey 2006), and accommodation needs (Barr, McConkey and McConaghie 2003). Semi-structured individual telephone interviews were conducted with staff from the service providers caring for the participants with ID. Supplementary qualitative data was also included from open-ended questions in family survey packs for 97 family members.

Topic guides for the focus groups and semi-structured interviews were devised using themes identified in the literature and via stakeholder involvement. All questions asked were open-ended to allow participants to answer freely, and prompts were used if participants had difficulty in formulating answers. Appendix 6 contains the qualitative interview and focus group for athletes and non-athletes. Family carer focus group topic guides can be viewed at appendix 9 and staff telephone interviews can be viewed at appendix 10. For comparative purposes across all cohort groups, the questions posed were similar. The main areas explored were barriers and facilitators to participation in SO, and the impact of participation on the lives of athletes and families.

6.2.1 Procedure

A total of 47 participants took part in the qualitative study comprising of 15 athletes, 11 family members of athletes, 6 non-athletes, 7 family members of non-athletes and 8 staff members. Inclusion criteria for athletes and non-athletes included the ability to engage using verbal skills that were sufficient to provide information about their thoughts and experiences of SO, and the ability to provide informed voluntary consent to participate. Athletes and non-athletes who were non-verbal were excluded. All participants were purposively recruited from four services providing support to people with intellectual disability in urban and rural settings in the Republic of Ireland (site A n= 11; site B n= 13; site C n= 15; site D n= 8). Athletes and family members, who had provided their contact details following an initial face-to-face meeting with the research team introducing the study, were contacted and invited to participate. Written invitations to participate were sent to staff members by the local gatekeepers (e.g. manager of day services) at each site. Staff interested in taking part made direct contact with the research team.

Written informed consent was obtained from all participants. For participants with ID (athletes and non-athletes), a user-friendly consent form employing images and simple text was developed in conjunction with an ID advocacy group experienced in conducting research involving populations with ID. In any situation where a participant had difficulty with writing and providing his/her signature, verbal informed consent was witnessed by two members of the research team.

Table 1: Qualitative data sources

Data Source & Participant cohort	**Focus Groups - Athletes**	**Focus Groups - Athletes' Family Members**	**Focus Groups - Non-Athletes**	**Focus Groups - Non-Athletes' Family Members**	**Phone Interviews - Service Staff**	**Open-ended questions in family survey packs**
Focus groups / Participant Numbers	n=5 n= 15	n=3 n= 11	n=2 n= 6	n=2 n=7	n=8	n=97

6.3 Data Analysis

Interviews were transcribed verbatim, with each participant being labelled via a code in order to preserve confidentiality. All data from focus group interviews, telephone interviews and open-ended survey questions were analysed thematically by drawing on a framework for thematic analysis which details the following five phases; data familiarisation, initial code generation, theme searching, defining and naming themes and production of the final report (Braun and Clarke 2006). This included listening (and re-listening) to, and transcribing, the audio-recorded files from the focus group and telephone interviews. Following this, the data was read and re-read, looking for any initial patterns or areas of interest.

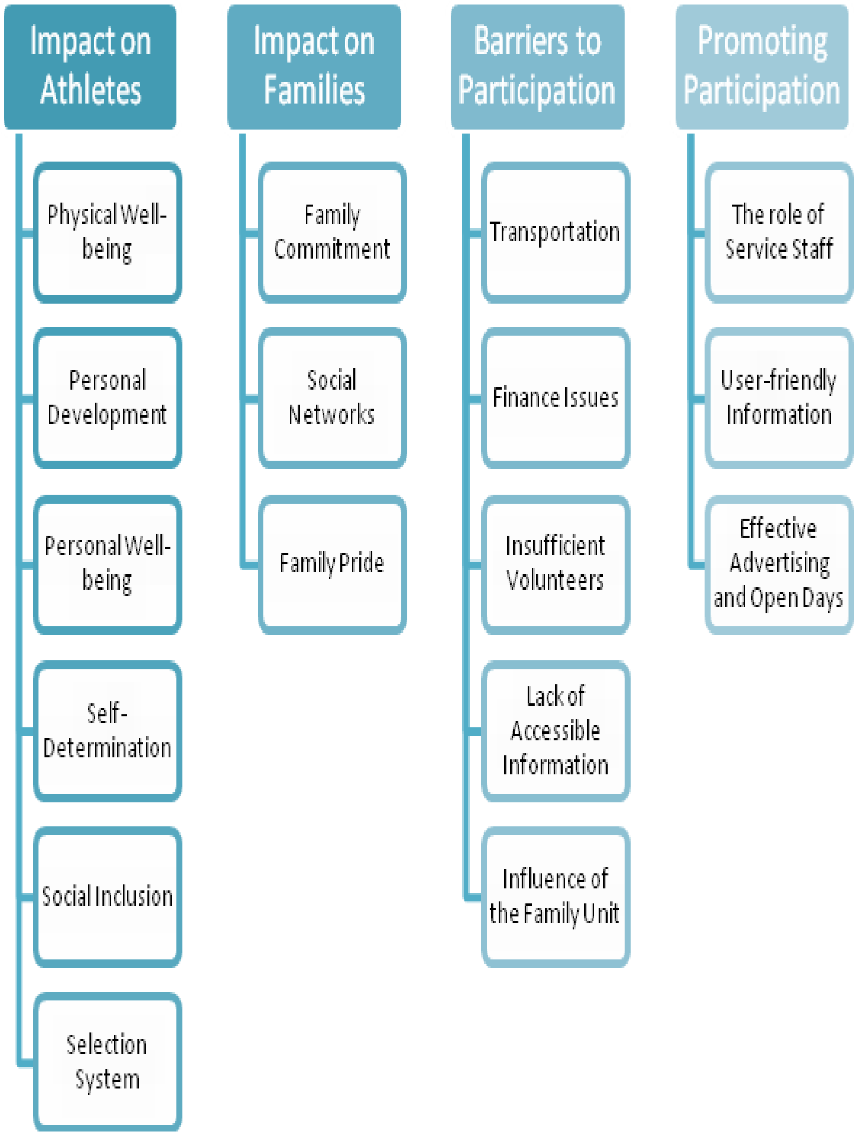
Each cohort was initially analysed individually i.e. athletes, non-athletes, family members. Following this, different cohorts were analysed together to compare and contrast views arising from each one, e.g. athletes and family members of athletes, non-athletes and family members of non-athletes, before looking across the entire data set for similarities and differences. This led to the generation of initial codes and the collation of these codes into potential themes using the qualitative data management computer package NVIVO. As the analysis process continued, provisionally-named themes were reworked, to hone in specifically on the core issue of that theme as emergent from the data; this was assisted by discussion among the research team and continuous referral back to the original raw data.

6.4 Findings

Four main themes emerged from the data: (1) impact on athletes; (2) impact on families; (3) barriers to participation in SO; and (4) promoting participation in SO. Within each theme a number of sub-themes were identified, and perspectives given from all contributing focus groups, individual staff member interviews and qualitative questions from the SOPHIE study questionnaires. The impact on athletes was reflected in sub-themes; physical well-being, personal development, personal well-being, self-determination, social inclusion and selection system. For families, the impact was detailed in sub-themes of family commitment, social networks and family pride. Barriers to participation identified were transportation, finance issues, insufficient volunteers, lack of accessible information and the influence of the family unit.

Three sub-themes for promoting participation were identified: role of service staff, user-friendly information, and effective advertising and open days. A description of the findings is presented in this section with extracts from the focus groups, interviews and questionnaire, while the significance of the findings is discussed in the next section. Figure 2 below visually displays all emergent themes and sub-themes.

Figure 2: Themes and Sub-themes.



6.4.1 The impact of participation in SO on Athletes

Physical well-being

Physical well-being in the area of health and fitness benefits were commonly identified by all the participants and seen to be a very positive aspect of being involved in SO. Athletes spoke about how participation in SO raised their awareness of fitness and diet, and had a positive influence on their attitudes towards these. In many cases, athletes were taking part in extra physical activity outside of SO, and when asked what they would do without SO many expressed that they would continue with some form of physical activity.

> *!If I didn't go to Special Olympics anymore, I'd go to the gym 3 times a week.*
> *And that would keep me active. I'd still go to that and I'd still do my*
> *walks in the mornings around town". (*Athlete)

Staff identified that athletes benefited from the physical activity offered.

> *"Definitely they're fitter". (*Staff member*)*

Family members of athletes relayed how being part of SO had made athletes more concerned about the types of food they consumed.

> *"It's the eating end of it. And now he'll be like I want chicken and pasta,*
> *I want what's healthy, what's good, to drink the water". (*Family Member*)*

Personal development

Personal development, such as the social aspects of SO appear to be equally, if not more, important than the sporting involvement, as expressed by the family members, staff and athletes. SO acted as a much-needed social outlet for athletes - for individuals with ID, social outlets are often limited. It gave athletes a chance to spend time with existing friends, make new friends and provided a place for them to socialise outside of the home, day services or work environments. Athletes reported that they would feel sad if they could no longer attend their SO club, mainly because they would not get to see their friends.

> *"Special Olympics is their social life like so much revolves around that"*
> *(*Family Member*)*
> *"I love to socialise in Special Olympics and meet new people that I do the activities with" (*Athlete*)*

Independence was a further aspect of personal development, with family members and staff reporting how athletes became much more independent as a result of their involvement with SO, due to socialising and travel with other athletes.

> *[Her son would say] "why don't you just go, leave me alone I'm here with me friends - off you go". (*Family Member*)*

> *"When there's a group of them as well they're given a lot more freedom or independence". (*Staff Member*)*

Personal well being

This theme mainly reflects the voice of family members. The theme emerged from an analysis of the SOPHIE survey's open-ended questions, which specifically asked family members to reflect on what being involved in SO has meant to their lives and that of their family member. Family members described how involvement with SO has provided their son/daughter/sibling with a sense of purpose or a focus in their lives. Family members felt that being involved in SO enriched athletes' quality of life by providing them with enhanced ambition and the motivation to work towards something.

> *"Gives him goal, ambition, determination to do well". (*Family Member*)*

Alongside providing athletes with a sense of purpose, participation in SO endowed athletes with a sense of belonging and community spirit, where they experienced a positive mind-set towards disability in a non-judgmental context.

> *"Very little places [I] can take [athlete and they are] not judged, it's the one place".*

> *[we] "can go and relax". (*Family Member*)*

> *"He has come out of himself completely". (*Family Member*)*

This sentiment was also echoed by an athlete who spoke of her happiness at finding her *'comfort zone'* when she joined SO.

> *"I was glad I joined Special Olympics 'cause I was out of my comfort zone and then I got in my comfort zone with Special Olympics". (*Athlete*)*

Many family members reiterated that participation in SO was the most important aspect of their family member's life. They alluded to how life was more fulfilling and generally more worthwhile for athletes as a result of being involved in SO.

> *"There's so many things that they cannot achieve, you know... but this is theirs". (*Family Member*)*
> *"To me it has been her life". (*Family Member*)*

Self-determination

Self-determination was seen in the value and meaning attributed to achievement. Having the opportunity to achieve in competitions was important to athletes. Athletes were keen to share their experiences about succeeding in competitions, and expressed pride and happiness at winning medals and ribbons. Many referred to the achievement of taking part.

> *"It was a big achievement for me".* (Athlete)

Family members also spoke of athletes' pride at accomplishing and its importance to them.

> *"The joy it brings them…when they get their medal*" (Family Member)

Social Inclusion

Being part of SO provided athletes with new opportunities such as travelling and media involvement. Travel was an integral part of the SO experience to athletes. Many shared their experiences of journeying to local training sessions, and to national and regional games. Other athletes spoke about their involvement with local media outlets, including newspapers and radio.

> *"Okay. Is there anything else about it that you like, about being an athlete or about training with your club"?(*Moderator*)*
> *"Going places. Then after that I got on the paper, famous". (*Athlete*)*

Both athletes and family members spoke of the community support shown to SO athletes. They spoke of how local people and local organisations got involved by, for example, sponsoring people to go to competitions and sharing in the success of local athletes.

> *"Every time she [local athlete] wins a medal it's put in our local parish newsletter… there's always big community support I find…" (*Staff Member*)*

> *"They done fundraising for me now at work and they're so happy for me, like everyone all over the town's so happy for me". (*Athlete*)*

6.4.2 Selection System

The process by which athletes are selected to advance to the next level of competition was viewed with disapproval by each population group – athletes, family members and staff members. Athletes are chosen using a random selection process, which is employed in order to ensure athletes of all ability levels have the chance to compete at all levels of competition. However, athletes expressed unhappiness with this system because they felt that it resulted in too few athletes being able to progress to the next level of competition.

> *"Everybody should get a chance to go… More names pulled out of the hats".*
> *"So really it'd be nice to get a few more people to go". (*Athlete*)*

Due to maximum quotas enforced in the random selection process, athletes who win a place at games may still be unable to progress to the next level of competition. One athlete expressed disappointment in such a case - after winning a medal at the regional games but not securing a selection place for national games.

> "*All the hard work. And they pick someone else*. (Athlete)

Similar to the apprehensions of the athletes, family members and staff felt that the random selection process was unfair because it resulted in only some athletes being afforded the opportunity to compete.

> *"You see some gifted Special Olympic athletes that never get a chance to go".*
>
> (Family Member)

Although family members and staff understood that this random selection process was necessary due to the high number of athletes in SOI, it was suggested that a fairer way to select athletes should be identified.

6.4.3 The impact of involvement with SO on families

Family Commitment

Both family members and staff discussed the level of commitment needed from family members in order for individuals to attend their SO clubs. Family members provided what was often the only mode of transport available to athletes and so had to allocate their evenings to escort their family member to and from training. A large number of family members also reported that they stayed at the training club to watch the athletes, with some reporting they got involved volunteering in different roles.

> "*You know wherever they're going they have to be brought and picked up and you've to wait for them*" (Family Member)

> "*I'm there too helping out*". (Family Member)

This time commitment not only impacts on the family member, but also on the whole family unit. Time spent accompanying an athlete to training, assisting them with additional training at home or travelling further afield from home to facilitate team training (for example, participation in World Games) left family members with less time to take care of other things in the home.

> *"It's a big commitment. We'll say you've got an athlete with a disability; you might have three others at home which you've to see to as well" (*Staff Member*)*

Social networks

SO provided a social outlet not just for athletes, but for their families also. It provided social opportunities to those whose options may be limited. Family members had the opportunity to meet other family members who were in a similar position to themselves to talk to and socialise with. Parents reported that it provided them with a sense of community, where everyone looked out for each other and shared their personal stories and experiences.

> *"Sense of community, positive feeling towards disability, lessening of isolation due to interaction with others in the same situation"* (Family Member)

Family members voiced their enjoyment at having the opportunity to travel to competitions such as national and world games to support the athletes and experience the atmosphere of such large communal events.

> *"You nearly love for them to get through, you know so you can get going yourself". (*Family Member*)*

> *"He was at [national games] in Limerick the last time out and we went down as a family, stayed overnight…It was a smashing, smashing day". (*Family Member*)*

Family Pride

Family members expressed their huge pride at their son's/daughter's/sibling's achievements. They enjoyed watching them compete. Competitions provided an opportunity for family and friends of athletes to come together and witness them accomplish at sport. Athletes also spoke about the pride they observed from their family members as they watched them, as athletes, participating and achieving in sport.

> *"All the families are very happy for, for their… son or daughter to be, to be part of those sports in the Special Olympics". (*Athlete*)*

> *"I'd say it could mean a lot more to the parents than it does to the competitors sometimes. Well you're proud of your offspring aren't you?" (*Family Member*)*

6.4.4 Barriers to Participation in SO

Transportation

Family members and staff participants described transport as one of the main barriers to athletes' participation in SO. Lack of available community transport was viewed as a key reason for preventing more people joining the clubs.

> *"It's an issue for quite a large number…I'm thinking of all the people I work with and off the top of my head, 5 or 6 transport is definitely the reason they can't get there" (*Staff Member*)*

Specific concerns were expressed about individuals with different living arrangements, for example those living at home with elderly parents or those in residential care. People living with parents who are older or dependent on staff were less likely to have access to transport on request or a staff member available to accompany them where they need to go.

> *"I suppose the age of their parents is going to affect them. Older parents mightn't be in a position to bring them". (*Family Member*)*

Finance Issues

Staff members reported that reduced funding in services impacted on how SO programmes are run. Cutbacks, in particular, resulted in reduced staffing which had a direct bearing on the amount of time staff could contribute to SO training.

> *"So the amount of training we're doing is not as much as it was… and the main reason for that is, is eh, cutbacks" (Staff Member)*

For families, the cost of sending athletes to national games was raised. Family members felt that this could be a financial burden for some families, and result in some athletes not being able to take part.

> *"I'd say it could stop some families… they mightn't like to turn around and say we can't afford it. (*Family Member*)*

Insufficient volunteers

Having insufficient volunteers was reported as an inhibitory factor that could prevent individuals from taking part in SO. Parents and staff highlighted that the number of volunteers had dropped in recent times. They felt that the availability of more volunteers would allow for a larger number of athletes per club, and could help solve the problem of transportation.

> *"Is the same support there as there was ten years ago? You know, I know there are lots of reasons, people who eh, give free time, they have to have time". (*Family Member*)*

> *"There wasn't enough people helping out, they couldn't take any more" [athletes]. (*Family Member*)*

Lack of accessible information

The main barrier to participation cited by family members of non-athletes was insufficient information about SO. They reported having little knowledge about SO, such as how clubs are run, nearby locations and eligibility to participate.

> *"The only thing I know about Special Olympics is we put money in at the traffic lights in the box". (*Family Member of Non-athlete*)*

> *"I just have no idea where they're on, what times they're on, who runs them, nothing". (*Family Member of Non-athlete*)*

A lack of knowledge concerning athletes was evident once family members' perceptions about SO were explored. Concerns over issues such as age and physical fitness arose, with apprehensions raised over whether their family members were too old or too unfit to take part.

> *"Thirty Seven is that not too late?"* (Family Member of Non-athlete)

> "*If he was fit to do it".* (Family Member of Non-athlete)

People with intellectual disability themselves also seemed to lack information on the different ability levels. They explained how they would not go to SO, fearing that it would be too difficult for them, with one individual revealing that she had once participated but quit as she felt unable to keep up.

> *"I think it would be too hard*" (Non-athlete)

Influence of the family unit

The influence of the family was cited as another barrier by family members of non-athletes. The age of parents was identified as a difficulty as the level of commitment to supporting the athletes may become too difficult to sustain.

> *"The younger the parents of these kids the more enthusiastic they are…*
> *There is a lot of cases where the parents are getting into their seventies*
> *and might have difficulty going from A to B and going places, or driving*
> *or anything like that. (*Family Member of Non-athlete*)*
> *"They're a long time doing that role of parenting... they don't have the energy".*
> *(*Family Member of Non-athlete*)*

Families may also have an influence on what interests people with intellectual disability. It was felt that if families were not inclined to participate in sport themselves, then the person with ID would be less likely to be introduced to sporting activities.

> *"If your family is really into sport, you'll be looking to join them into*
> *something… none of us are sporty so we never would have been drawn*
> *towards sport, so that's probably why, a reason why she's not in it"*
> *[Special Olympics]. (*Family Member of Non-athlete*)*

6.4.5 Promoting Participation in SO

Role of Service staff

Throughout the findings, staff also highlighted positive benefits and challenges with selection and barriers to participation in SO. Some results were of particular relevance to staff. They saw a role for themselves in supporting and advocating for people with ID in SO but also in seeking mainstream rather than segregated opportunities. They pointed to the opportunities for building skills in areas such as teamwork and communication that SO can offer. Their advocacy role was evident through much of the interviews with examples given of when they supported people either to join or remain involved in SO.

> *"So they need somebody to support them and stand up for them, put their names forward and work at giving them the opportunity to take part2. (*Staff member*)*

Staff identified with the need to promote and encourage involvement but also wanted to support athletes to remain involved if difficulties arose. The extract below is an example of how a staff member advocated for an athlete who was having difficulty remaining in her lane but who really enjoyed participation.

> *"…we have a situation where one girl isn't great for staying in the lanes and she (coach) has brought it up several times and she's tried to bring it up at the national games. But I stuck to my guns and I have said that basically it's about participating it's not about winning medal" (*Staff member*)*

A further example of staff identifying with particular athletes was when one staff member spoke of people with a mild ID becoming involved in SO due to limited opportunities in mainstream. Here again, staff saw a role as an advocate for the person with ID.

> *"Particularly people with mild intellectual disabilities... and who may have an absolute passion for a sport. But for a variety of reasons, cannot manage to get the level of participation they want at mainstream. They resort to participating in Special Olympics. And find that a lot of the rules which are applied, they find them bizarre. And if they express that they kind of don't like these rules, or that these rules are unfair or that these are not the rules that we want, then they ask people like myself to advocate for them. They're not happy with the response that, these are the rules and if you don't like them tough". (*Staff member*)*

The role of staff can be seen as significant in many aspects of supporting people who participate in SO, which may impact on their participation.

User-friendly information

Athletes conveyed the importance of having an established link person within each service. The link person is normally a member of staff within the service provider, who is the main point of contact regarding SO participation and training. Athletes felt that knowing who to consult for more information, and added knowledge of how to initiate the registration process with SO, would enhance the accessibility of SO.

> *"Well if they could phone up [a link person] and she'd give you the form and you'd*

> *fill it up". (*Athlete*)*

Staff members' perspectives on promoting participation were mainly concerned with having sufficient information about SO, in particular in relation to how it operates. Staff felt that clear, accessible information should be available to potential athletes in order to ease any concerns they may have about joining; most notably in the area of '*divisioning*' (i.e. a process that ensures all athletes compete with other athletes of similar ability).

> *"I think people need to see that you can compete at your own level, not you know, you can't have a person that can run two miles up against a person that can only run maybe twenty yards". (*Staff Member*)*

Family members of non-athletes stressed the need for more information to be made available to service users and their families about SO. Family members felt that information should be provided to all service users, which would include details of how SO is run, where to find them and how to register, an idea echoed by one non-athlete and staff member.

> *"Have it all [information about Special Olympics] written down on a bit of paper". (*Non-athlete*)*

> *"…maybe some easy to communicate information…if this was sent out to the units". (*Staff member*)*

It was also suggested that the service providers play a greater role in providing clients with information about SO. The non-athletes interviewed reported that to date, nobody from their service had suggested they join SO. Family members accepted that the SO website provided information. However, they acknowledged that not all individuals have access, or the inclination, to use the internet.

> *"There's a lot of people too that don't have access to computers… [there should be] information laid out for people who can't just press a button and it all comes up on the screen". (*Family Member*)*

Staff also identified that lack of information could be an issue for some families.

> *"There might be some people who have a lack of information and what it (Special Olympics) entails" (*Staff member*)*

Effective Advertising and Open Days

The family members of non-athletes suggested that SO conduct large-scale advertising through the media, to recruit athletes as well as to provide general information about the organisation. Family members concurred that holding open days where individuals could try out different sports might be an effective way to recruit new participants.

> *"If it was in your face, in your car, in your kitchen then you might say oh that's where I'd go or that's where I'd make an inquiry to".*
> *(*Family Member of Non-athlete*)*

> *"I mean there has to be a nationwide campaign…we need you basically, Special Olympics needs you". (*Family Member of Non-athlete*)*

The concept of holding open days was also suggested by athletes, who felt that individuals should be allowed to visit clubs for a trial to "*try them out*" to see if they would like to become involved on a regular basis. One athlete stressed the importance of making new athletes feel welcome in the club so that they would want to continue to participate.

> "*Being nice to the young new athletes".* (Athlete)

Athletes felt that more clubs should be available locally, a suggestion supported by family members, so that individuals who did wish to join a club did not have to travel far to do so.

6.5 Discussion

This qualitative component of the overall SOPHIE study aimed to investigate the impact of participation in SO on athletes and their family members, and to explore factors which are perceived as barriers and facilitators to participation. Overall, the findings reflect some of the previous studies that identified the impact on athletes and their families of involvement in SO.

Participation in SO has been found to benefit athletes and their families (Glidden et al. 2011). An American study reported on the contributions of SO to the family, and the findings identified the positive impact of being involved for both families and athletes. Generally, families saw SO as very beneficial, making them feel proud while highlighting the strengths and abilities of their family members, raising their expectations of them and offering opportunities for increasing skills. Increased social networks, friendships and community participation were also seen as positive aspects of involvement (Kersh and Siperstein 2012). In 2008, a Latin-American study also found families felt more positive and athletes benefited from improved skills and relationships (Harada et al. 2008b). Similarly, this study has identified features of SO involvement as being mainly positive for athletes and their families. Improvements in physical and personal well-being, personal development, self-determination and social inclusion all point towards increased quality of life for people with intellectual disability. Families' quality of life has also benefited with commitment to SO, pride in athletes' achievements and increased social networks. Quality of life has been defined as:

"A multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people, although they may vary individually in relative value and importance. The assessment of quality of life domains is based on culturally sensitive indicators". (Schalock and Verdugo, 2014, p.38)

The principles of this definition highlight that quality of life is common to all, and that everyone experiences a good quality of life when their needs are met and life is meaningful and enriching. Quality of life can be measured by examining indicators in everyday life, which include opportunities to be an active member of society and to be included in the community. This is reflected in the mission and vision of SO who, through sport, seek to provide opportunities for personal development and social inclusion for people with ID. The quality of life factors of independence, social participation and well-being are evident throughout much of the participant data, with many examples of how involvement with SO has added to the quality of life of athletes and their families.

While the findings are highlighting these improvements, some aspects are worth further consideration, as they reflect much of the national and international literature and policy, which is indicating that people with intellectual disability should be supported to reach their full potential and enjoy a good quality of life. In the Republic of Ireland for example, the *New*

Directions report focused on day services for adults with disabilities, identifying important aspects of supporting people to have meaningful and valued day activities. The core values of the document were "*person-centredness, community inclusion, active citizenship and quality"* and that these values form… *"the foundation of support for adults with disabilities…" (Kinsella 2012, p.71).*

In the UK in 2001, the *Valuing People* strategy document was published, which also highlighted the importance of person-centred approaches as the way to improve the quality of life for people with disability.

With regard to leisure and relationships in particular, there is a recognition that leisure can contribute to "*…improving quality of life, can help to tackle social exclusion, and encourage healthy lifestyles" (Department of Health 2001, p. 80).* Indicators of positive quality of life are found in activities that promote independence, social participation and well-being (Schalock and Verdugo 2014). The athletes in this study have reflected many indicators of the impact of participation in SO as positively affecting their quality of life. New social relationships, a group setting where athletes feel welcome and accepted, achieving at games and winning medals are all experiences athletes have gained through SO, all of which help contribute to emotional well-being. Family members have spoken of how involvement in SO can occupy an athlete's life fully, and that it is an opportunity for them to attain goals valuable to them and to reach their full potential. Therefore, it could be argued that SO is playing a key role in meeting social and emotional needs and improving quality of life, which can potentially translate into an economic saving for a health budget.

Common to all athletes, their families and staff was their concern with the selection system employed in SO. Although athletes, family members and staff acknowledged the difficulties with selection, there was concern that this may de-motivate athletes and that a system that reflected the effort of individual athletes should be considered and explored to improve athlete satisfaction.

The impact on families of having a child or sibling who participates in SO can be considerable, as evidenced by the data in this study. Having a family member join SO often results in parents or siblings committing significant time to the organisation. Many family members become involved in volunteering and chaperoning, which can leave them with less time to take care of other requirements and people in the home. A further consideration when looking at the impact on the family is the amount of time an athlete may continue to participate in SO, as the method of "*divisioning*" allows athletes to compete until old age. This will impact on families, as athletes will continue to require transportation or chaperoning, resulting in older parents having to maintain a commitment they may find difficult or impossible.

Family members are also benefiting from their involvement with SO. It gives them an opportunity to take pride in their family member's achievement and also expands their social networks. This is an important finding, as previous research has shown that family members' or carers' social lives are often limited due to caregiving responsibilities (Caples and Sweeney 2011). SO provides families with an outlet to meet others who can understand their situation. However, this is the type of outlet to which family members or carers are often restricted (Yoong and Kortisas 2012), and is not necessarily something they might choose themselves, or which their peers are involved in. This does not mean that the relationship between family members and SO is not a positive one; in fact, research has found that being involved with SO could be acting as an additional support to parents (Weiss 2008), and families identified the motivators for participation as being fun and socialisation (Siperstein et al. 2005). This study supports these findings, in particular the opportunity to take pride in the athlete's achievements.

The impacts on families as indicated are not always positive and many of the barriers to participation impact on families as well as athletes. The main barriers to participation reported were transportation issues, funding problems, insufficient numbers of volunteers, lack of accessible information and the influence of the family unit. Logistical issues such as transportation, having volunteers or chaperones available to supervise activities as well as the financial reasons behind such issues were reported as a major barrier to taking part in physical activity in many studies (Downs et al. 2013, Bartlo and Klein 2011, Mahy et al. 2010, Temple and Walkley 2007). Dowling at al. (2012b), in a literature review undertaken for SO to examine the relationship between physical activity and well-being, identified some similar barriers regarding financial constraints, transport and information needs.

An increase in funding and volunteers would likely lend to the improving of logistical problems such as transportation and chaperones, allowing for larger numbers of athletes to take part. Family members of non-athletes described how little information they actually knew about SO. They were unclear of basic facts about SO such as how it is run, where they could find it, how to register and who can participate. This indicates a strong need for easily accessible information if SO want to encourage greater numbers to participate. The families' suggestion of a "try-out", coupled with staff suggestions of providing more information about SO is worth noting This finding is significant as it relates to the relationship between service providers, families and SO. Sharing of information can depend on the particular service being used by a person with intellectual disability and that service's commitment to SO.

Promoting participation was an important finding, in particular the role of staff and the need to have more accessible information about SO available. Better information from SO needs to be made available to all individuals with ID, their families and service providers. For staff, their role in promoting participation was a key feature as they encouraged and supported participation, while also advocating for people who may be experiencing difficulties with SO. In services for people with ID, staff are tasked with ensuring that an individualised approach is taken to everyone they support, and this includes a plan that includes opportunities for physical activity (Schalock and Verdugo 2014). The staff interviewed for this study valued SO, while also pointing to the barriers for participation and the move towards mainstream rather than segregated activities.

Although information is available on the internet, some participants spoke of how that is inaccessible to many parents as they do not use it. Digital literacy and/or social IT skills and motivation to use digital mediums could be a common problem for older family members across Ireland, as it has been shown that many older people do not know how to use the internet, and have no interest in doing so (Martinez-Pecino, Delerue Matos and Silva 2013). Service providers could play a greater role in ensuring service users, and in turn their families, get sufficient information about opportunities such as SO.

It is therefore important that any care providers have adequate information about the subject. This would also ensure that all service users would receive the same information, not just those with younger, more enthusiastic parents. Stronger advertising campaigns and conducting open days in clubs were also suggested as ways to promote participation. Ensuring effective advertising is essential, as family members and care staff who support people with ID play the main role in identifying opportunities to engage in physical activity (Stanish and Frey 2008).

A lack of information could again be a reason for the unease concerning how athletes are selected. All participants expressed unhappiness with the current selection system, a random selection process to fill the quota allowed for the next stage of competition. If the number of medal winners exceeds the allowed quota then random selection takes place, leaving some medal winners dissatisfied. Again, detailed information from SO about how the process works and why, might help alleviate some of the distrust and discord surrounding it.

This study has shown that overall SO impacts positively on athletes and their families, with staff making a significant contribution to supporting participation. Concerns exist with the selection process used in SO, and this was highlighted by everyone interviewed. Barriers were also identified, with particular difficulties relating to transport, volunteer shortages and demands on older parents.

6.6 Limitations

While the study team were successful in recruiting ample numbers of athletes and family members to partake in the research, it was much more difficult to recruit non-SOI members;

as a result only two focus groups were held with non-athletes. This made it more difficult to ascertain barriers from their perspective. Reasons for the low uptake of non-athletes included competing priorities, unavailability, inability to contact, insufficient verbal communication skills, respite stay, illness, non-attendance at interviews, geographical spread of participants and transport issues. Similar recruitment difficulties within this population have also been previously documented (Lennox et al. 2005).

6.7 Conclusions and Recommendations

Involvement in SO contributes to improved quality of life for people with intellectual disability as it offers opportunities for increased independence, widens social networks and contributes to emotional and physical well-being.

Participation in SO is valued by athletes, families and staff with the positive benefits extending beyond the physical activity to aspects of quality of life that involve personal development and in particular opportunities for positive social interactions.

The selection process with SO needs to be considered by the organisation as there is a general dissatisfaction with the current way in which athletes are chosen for competitions. This may involve better communications as well as a review of the current system.

For staff who work with athletes, they see their role as an advocate as well as a supporter of people with ID, and this is a positive and encouraging finding as services strive to provide person-centred services.

Reducing barriers to participation involves addressing issues of transport, costs associated with being involved, increasing volunteer numbers, identifying and addressing issues of particular concern to older parents and providing accessible information to attract more athletes. There needs to be an acknowledgement that current methods of communicating information are not always effective and SO should consider identifying additional ways of promoting participation.

Overall, while the benefits of SO involvement are clearly evident throughout this study, challenges exist that need to be addressed if the vision of every person with ID having an opportunity to be involved in sport is to be achieved.

7. Report 5: SOPHIE (Special Olympics Programmes Health Impact Evaluation) Study: focus group findings on how SOI have addressed PA participation barriers

7.1 Introduction

The purpose of this section of the SOPHIE study was to conduct a focus group to examine how SOI management have addressed PA participation barriers for people with an ID. These barriers were specifically identified through a literature review report commissioned by SOI and written by Dowling et al. (2012b). It is important to stress that the aim of the focus group was not to identify PA participation barriers per se. To this end, a summary of the identified barriers from the aforementioned report will be outlined below. For more detailed information, please refer to the Dowling et al. (2012b) report.

In summary, the literature review report consisted of seventy-four papers. Fourteen of these papers focused on barriers and facilitators to PA participation for people with an ID. All papers were published in peer-reviewed journals between 1990 and the present day. Identified barriers were divided into three categories: 1) environmental barriers, 2) structural barriers and 3) personal barriers. Environmental barriers included lack of access to facilities and equipment (Howie et al. 2012), financial constraints to participate in PA for people with an ID and their family (Barr and Shields 2011), transport (Bodde and Dong-Chul 2009), time (Hellar et al. 2002) and inclement weather (Temple 2007). Structural barriers included a lack of adequate support for people with an ID to engage in PA. This encompassed lack of family support (Barr and Shields 2011), lack of care provider staff support (Mahy et al. 2010), lack of policy surrounding the area of PA provision for the ID population (Temple and Walkley 2007), people with an ID having to rely on others to engage in PA (Messent et al. 1999), impact of staff attitude and knowledge towards PA (Temple and Walkley 2007) as well as difficulty experienced in accessing programmes (Barr and Shields 2011).

The final category of barriers identified was personal. This included people with an ID being disinterested in PA (Mahy et al, 2010), people with an ID feeling exercise participation is too difficult and lacking competence to participate (Temple and Walkley 2007) and feelings of frustration at not having freedom and independence to engage in PA, primarily due to reliance on support from others (Messent 1999). It is important to state that the focus group did not address every individual barrier; rather it addressed agreed key barriers which will be detailed below.

7.2 Methods

A focus group was held with 5 members of SOI staff. The participants were purposively recruited by a SOI senior staff member. Three participants were senior management staff of SOI, the fourth participant was a regional development officer of sport and the fifth was a trainer manager. The focus group took place in SOI head office and was 70 minutes duration. All participants were read a plain language statement and signed a consent form prior to focus group commencement. The focus group was recorded by Dictaphone and was facilitated by a trained researcher.

The discussion was guided by topics identified through literature on PA participation barriers for people with an intellectual disability, particularly those identified in the Dowling at el. (2012b) report, as well as questions pertinent to the organisation of SOI. As the purpose of the focus group was to examine how SOI addresses PA participation barriers, the drafting of the focus group guide was based on the premise that participants would be aware of the identified barriers highlighted in the Dowling et al. (2012b) report. Prior to the focus group, a draft topic guide was circulated to all SOPHIE researchers for feedback and following amendments, the final topic guide was drafted. Questions were open-ended in nature and prompts were used if necessary. All study materials for this element can be viewed in appendix 13.

7.3 Data analysis

The focus group interview was transcribed verbatim. Data was analysed using the constant comparative method (Merriam 1998). Constant comparative analysis allows a researcher to format and transcribe data into a readily identifiable, readable and structured format. This analysis uses systematic steps of identifying key points, followed by comparing these points with those of other focus group members in order to identify patterns. This structure ensured that what was presented was an accurate reflection of the focus group participants' views. Data was reduced in order to determine themes and provide a means by which rich information could be retrieved (Dunning et al. 2011). In order to ensure data trustworthiness, peer examination of the data occurred between researchers to ensure individual researchers found similar findings.

7.4 Findings

Three key themes were identified from the focus group: 1) previously identified PA participation barriers for people with an ID were not recognised as being barriers impacting SOI athletes, therefore they were not specifically addressed by the organisation, 2) some participation barriers were acknowledged, but were viewed as not within the remit of SOI to address and 3) some participation barriers were actively addressed by the organisation. At the start of the focus group, participants were asked what they knew about the Dowling et al. (2012b) report identifying PA participation barriers for people with an ID (the report was commissioned by SOI). All 5 participants were aware of the existence of the report but no one could provide any detail on it or the identified barriers. This lack of knowledge resulted in the focus group facilitator having to describe the barriers in order to provoke discussion on how SOI addressed them.

In relation to theme 1, access to facilities and equipment as well as financial constraints were identified as environmental barriers in the Dowling et al. (2012b) report. When participants were asked how SOI addresses access to facilities and equipment, it was viewed as not being a participation barrier.

"I don't see that we have lack of access. I mean, we're a national governing body and we have the same access as anybody else… So, and from our clubs perspective, no club has ever come to say that they can't get, that I'm aware of, that they can't get access to a facility"… I'd nearly say hand on heart that there are no athletes or clubs that don't want to take part in sport that can't make those facilities or find those facilities. (Participant 1)
Since I've been in the organisation, it [equipment] has always been available to clubs. So finances and in terms of purchasing equipment that's never been a challenge for the clubs, I wouldn't think". (Participant 2)

On the barrier of financial constraints that people with ID and their families experience in relation to participation, it was contended that this was not a barrier for SOI athletes or their families.

"*Well from a Special Olympics point of view, no athlete can be debarred from participating through lack of finance. That's never been an issue for us"*. (Participant 1)
"…because of that protocol that an athlete shouldn't have to pay to participate at any level, it does put the onus back on the organisation to find the funds. The athlete can still participate free, but Special Olympics have to find the money to do that…That's the impact of a no cost access to an athlete…" (Participant 4)

In relation to theme 2, Dowling et al. (2012b) identified transport (environmental barrier), the role of the service providers and the impact of policy (structural barriers) as participation barriers for people with an ID. Focus group participants felt these barriers were outside the remit and indeed control of SOI as a national governing body of sport and therefore did not directly address them. In relation to transport, participants stated:

“Do we have a duty of care to go and set a bus up? No we don’t”. (Participant 3)
“*We’ve never got involved in transport. Deliberately because, we couldn’t manage it apart from everything else”.* (Participant 4)

Regarding the role of the service provider, participants stated:

“I think it’s important to remind ourselves what Special Olympics is. We’re a provider of sports training and competition for people with an intellectual disability… And our remit is to provide it, our remit isn’t to solve the problems of the services and we cannot go into the services or the schools or the workshops etc. and say you must attend” (Participant 1)

Further to this, an interesting finding from the focus group was how the participants viewed the role of the service provider and how disability policy impacted on SO and PA participation for people with an ID. Focus group participants acknowledged the barrier of SO athletes, and service users, being reliant on service providers to support them in engaging in PA:

“*It depends on the service and it totally depends on their interest in sport… and again this depends on the interest of the staff in the community house. And you know, I would have had experience of that over the years and it’s still happening. And if I’m interested in sport, I’ll get the car out or the bus or whatever it is and I’ll take them to the swimming club. Or take them to whatever it is, because I want them active. That’s going back to the seventies, and it hasn’t changed”* (Participant 1)

Focus group participants also highlighted the impact policies were having on SO participation. The issue participants raised was that of a change of policy direction relating to the integration of people with ID to community based settings. It was felt that this was inhibiting participation for some athletes as the community setting may not have the resources available to support athletes in accessing SO programmes.

“*…it’s been driven by policy in the last couple of years as to where the focus for the services has been told, you have to get people community based… but they’re also being impacted by the interactives coming down from the HSE and through HIQA as regards, you know, kind of community integrated services for their athletes versus service based integration”.*
(Participant 3)

“*Planning around the six or eight people who are going to be in that community housing is around accommodation, maybe access to transport, how many staff will be needed. It’s not the first thing in their mind that how can we look at a local Special Olympics club being involved here”* (Participant 4)

In further discussion of this topic, participants felt it was not SOI’s role to get involved with the service providers in looking to increase participation for its athletes or other people with an ID. They viewed their role as a national governing body of sport that provides programmes and has no remit in directly supporting disability organisations in helping athletes access these programmes:

“*And I go back to that because we’re not a disability service provider. We’re a sporting body providing sporting opportunities in the community...And a challenge is that you have four or five guys or girls in the community house for respite for the week or in residence and they all might want five different activities, but with one staff member, they can’t go in five different directions. So choice for the athlete goes off the board…we have worked with them and we continue to work with them in terms of going out there and seeing how we can support them within their local community or maybe expanding or developing additional sports within the community based clubs to absorb some of the athletes, to give them the opportunity to participate in sport or seeing how we can integrate them in it.. But as [Participant 1] says, we’re not a service provider”.* (Participant 3)

On a final note in relation to disability policy in the Republic of Ireland and SOI influencing such policy, when probed on whether they thought they should have a role in this, although participants didn't categorically state they were not interested in doing so, they seemed reluctant to play a role in this instance. They appeared unsure of their role and were not proactive in this regard, suggesting it was the role of service providers to influence policy more so than SOI:

"I would feel that the question you posed [What role you feel Special Olympics has or should have around policy or formation of policy decisions at a national level?]… because we're not a service… And I suppose that's where, if you muddy the waters in regards to are Special Olympics directors, and we would contribute to anything that we can contribute or if we're asked for an input we will input. But we're not the service providers". (Participant 3).

"*But all of the [policy] consultation, the representation is taken up with the national federation of voluntary bodies which are the service providers* (Participant 4)

In relation to theme 3, Dowling et al. (2012b) highlighted personal barriers which were similarly acknowledged by the focus group participants. These barriers were being addressed by SOI and highlighted how the organisation considered the welfare of athletes. The personal barriers SOI addressed included lack of autonomy amongst SO athletes and people with ID to engage in PA.

In relation to the barrier of lack of autonomy to engage in PA and the impact this can have on athlete welfare, participants stated:

"*Put it this way, in our own club we have seen where, not many, but the parents would come along and they would drop their son or daughter down there. Now it's quite obvious in some cases that the son or daughter doesn't want to be there but the parents want them involved… But the one I think that, that really people watch, our volunteers, is if an athlete is being pushed against their will to participate in a sport. And I think that's where we do, I think all of our volunteers would spot it or they'd come to a regional office and say what do I do, I've a parent who's dropping them at the door and we've to look after them*" (Participant 4).

"*And only two weeks ago I had a conversation with a parent and I said "Have you actually looked at the effect of it on your son?" And he's young, he's very young. And I know we all want to be involved in loads of sports to get an idea of what we want to do…we're not trying to make professional athletes out of our athletes but we do have to question when we see that they're in so many sports and the effect that that is having on them".* (Participant 1).

7.5 Discussion

This focus group aimed to examine how SOI as an organisation addressed PA participation barriers for people with an ID. This aim was established by looking specifically at the barriers identified in the Dowling et al. (2012b) report. It must be acknowledged that the report reviewed seventy-four studies examining the impact of physical activity and sport participation on the health and well-being of people with ID. These studies were sampled from various countries worldwide including Europe, Australia, Canada, Asia and the Middle East but were predominantly studies from the USA (n=34). No studies included in the review were from Ireland so it is difficult to determine which of the identified barriers are specifically applicable to an Irish context. However, upon examining the overall identified barriers from the report, SOI didn't address some of the environmental and structural barriers. This included namely access to equipment and facilities and financial constraints as they were not recognised as barriers. Participants did recognise some of the barriers, notably transport, policy impact and development as well as the role of service providers, but expressed they were either not within the remit of SOI or they were reluctant to address them. They did, and continue to do so, address some of the identified structural barriers. This focused particularly on those surrounding lack of self-determination some SO athletes experience, as well as exhibiting a duty of care for athlete welfare who may not have the capacity to look after their own well-being when participating in PA.

The finding that focus group participants believed access to facilities, equipment and financial constrains were not PA participation barriers was contrary to previous research findings. Research has highlighted that all these factors have a negative impact on participation for people with an ID (e.g., Mahy et al. 2010, Bodde and Dong-Chul 2009, Messent, Cooke and Long 1999).

At this point of the discussion, it is necessary to critically reflect on the organisation of SOI to contextualise the current findings. The mission of SOI is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with an intellectual disability, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendships with their families, other SO athletes and the community. The organisation's vision is to build the programme offered by SOI so that every person with a learning disability (or ID) has the opportunity, in their local community, to participate in high quality sport and development activities that bring life-changing experiences of increased skills, self-confidence and joy. Based on the findings of this focus group, SOI fulfil the organisation's mission and vison. They are a national governing body (NGB) of sport, providing PA and sporting opportunities for over 9,000 people with an ID.

The role of NGBs is to organise and administer most of the organised sport in Ireland. They train and deploy coaches; they organise representative level sport and they provide sporting opportunities and pathways leading from local sport to national and international competition (The Irish Sports Council 2015). Based on this, one must question whether it is within the remit of a NGB of sport to extend its role to address barriers beyond those associated with the above role. For example, Dowling et al. (2012b) identified transport as a participation barrier. Findings from the focus group highlight that this is not addressed by SOI, as arguably this is not the role of the organisation, or any NGB for that matter. Similarly, the role service providers can play in impacting PA participation was identified by Dowling et al. (2012b) but again, focus group participants argued that it wasn't their role to increase the numbers participating in SO. With this in mind one must objectively recognise the role of SOI as a NGB and question whether they have a role in addressing all barriers to PA participation for people with an ID.

7.6 Limitations

A significant limitation of this study was that a small number of SOI staff, mainly those in senior positions, actively participated in the focus group. In order to get a truer understanding of how the organisation as a whole addresses participation barriers, other staff levels within the organisation ranging from senior management to volunteers, athletes and families need to be included.

A further limitation was that none of the focus group participants were knowledgeable about the findings of the Dowling et al. (2012b) report and so were not aware of the identified participation barriers for people with an ID. The focus group was established on the premise that participants would have this knowledge.

7.7 Conclusions and Recommendations

SOI is a NGB of sport who provide sporting opportunities for people with an ID to participate in PA and sport. This is the role SOI adheres to and in so doing, does not address participation barriers that extend beyond that. SOI does not deem access and financial constraints as participation barriers for its athletes. This is contrary to findings from the SOPHIE study and the Dowling et al (2012b) report. Consequently, it is recommended that SOI give consideration to the barriers of access and financial constraints. Special Olympic Ireland should examine how the organisation can address these barriers to reduce the impact they have on athletes and families accessing and participating in SOI programmes.

8. Report 6: SOPHIE Study: Economic Report on the estimated economic costs of running Special Olympic programmes in Ireland.

8.1 Introduction

The international organisation SO was founded in the USA in the 1960s, with the aim of providing year-round sport training and competitions for athletes with an intellectual disability. SOI was founded in 1978 with the first clubs set up about a decade later. At the end of spring / beginning of summer 2014, the organisation had a total of 9,361 athletes, participating in 15 different sports in 385 clubs throughout the island of Ireland, with the support of a network of more than 25,000 volunteers.

Regional Offices. Due to expansion of the organisation, in addition to the Central Office for SO, regional offices began to be set up in 1995, beginning with Munster and Connaught. Today there are 5 regional offices: Eastern (which covers the greater Dublin area), Leinster (which incorporates the province of Leinster excluding the area covered by the Eastern region), Munster, Connaught and Ulster.

The impact on SOI of world games being held in Ireland in 2003. A major milestone affecting expansion of SOI was the successful bid for Ireland to host the International SO Summer games in 2003. This was the first time these games had ever been held outside the USA and approximately 7,000 athletes from 150 countries competed at the games held in Dublin. The opening and closing ceremonies were broadcast live for the first time ever; the event captured the interest of the Irish population, and was responsible for a large surge over subsequent years in the founding of clubs and the increasing participation of athletes and volunteers in SOI.

SOI clubs. SOI as an organisation could be considered to be similar to the Gaelic Athletic Association. Hundreds of clubs have been set up throughout the country which are affiliated to SOI, but are entirely responsible for their own finances, training programmes, etc. In order to participate in SOI competitions, it is a requirement that the person with an intellectual disability has trained for a minimum of 8 weeks, and is a member of a club which is affiliated to SOI. There are two major types of club, those classified as Service Provider (SP) clubs or Community-based clubs (CBCs) which are described in more detail below.

Service Provider (SP) clubs. A service provider club is an already-established centre or school which caters for those with an intellectual disability, who elect to run training programmes so that their pupils/residents can take part in SO competitions. The coaching is provided by the staff, which in turn is generally directly government-funded, and volunteer time is generally not a major feature. Such clubs may offer training for athletes to continue throughout the summer months.

Community-based clubs (CBC). A community-based SOI club is set up in a local area by members of the community. It is entirely dependent on volunteers for all aspects of sports coaching, and is largely dependent on club subscription fees from athletes and local fundraising initiatives/donations to cover the costs of running the club, which include such items as insurance cover, SOI affiliation fees, the hire of a venue for training, costs relating to sending athletes and coaches to competitions (both competition entry fees and transport). These community-based clubs are likely to offer programmes around the school calendar, closing for the summer months and re-opening for a new club year in September.

The four-year advancement cycle. All over the world, SO operate under a four-year "advancement" cycle. During the four year cycle in Ireland, athletes progress from Area (local) competitions, to Regional competitions, to all-Ireland games and finally to the international World Summer Games, whereupon the cycle commences again. Additionally, in the late winter/early spring of Year 2 of the cycle (Regional Competitions), SO World Winter games are held. This is a much smaller event than the World Summer games, especially in terms of participation by Ireland where winter sports are not prominent, and features competitions in sports such as alpine skiing, cross country skiing and snowboarding.

8.2 Aims

The SO Programmes Health Impact Evaluation (SOPHIE) study is designed to assess the impact of taking part in SO programmes in Ireland. This economic analysis carried out as part of the SOPHIE project aims to examine the average annual costs of running SOI programmes centrally and to explore the value generated in return; volunteer time is given for free, but is generated by the SOI programme.

8.3 Objectives

1. To access the administrative data held by SOI in order to:
    a. Capture club profiles, athlete training times, and volunteer time provided
    b. Capture financial records for SOI in the recent past, in order to be able to assess the costs required to run the programme.
2. To merge data from both of the sources (above) to estimate the cost of running SOI and to assess the annual unit cost per participating athlete.

8.3 Methods

An initial part of the study of the finances involved required acquiring a grasp of the historical growth and organisational structure of SOI which was presented in the introduction and below.

This base-line information was required to estimate the direct cost of providing SOI programmes in Ireland and was an important precursor to examining whether SOI is cost-effective (i.e., whether SOI represents value for money in terms of benefits generated).

8.3.1 Data sources:

1. Direct national costs of SOI (does not include club level expenses)

Aim: To appraise the national financial records to indicate cost per active athlete

Data:

- Information on Central SOI Financial Records
    - End of Year (cycles)

This did not include club level on athlete training times and so was estimated from data collected from a survey administered to clubs on athlete training times (details of this are included later in this sub report).

Analysis: We appraised SOI finance data over the four year cycle to disentangle what proportion of budget is directly related to supporting participations in on-going training and what budget relates to organising events. Both costs are provided by year and a disaggregated mean (and min—max range) cost of ‘on-going’ training will be used as the direct national costs of SOI for a subsequent *per capita* cost of SOI participation.

8.3.2 Data on Athlete participation

Aim: To appraise the number of nationally registered athletes and from which, estimate the number of which are active within at least one club.

Data: SOI holds its primary data on athletes, clubs and volunteers in a commercial database called The Raiser’s Edge (https://www.blackbaud.co.uk/notforprofit/fundraising-crm/products/the-raisers-edge). The Raiser’s Edge system is primarily designed to facilitate not-for-profit organisations in the management of their fundraising activities. There are hundreds of inbuilt fields for data entry, many of which are unused by SOI. Unique identifier data on athletes, volunteers, and clubs are all kept in a “records” table and the complex relationships between these entities described in a “relationships” table. Ideally, data was required specific to each of the four years 2010-2013 inclusive, to parallel the financial records being analysed (as it was apparent that SOI expenditure varies considerably over a 4-year cycle). Raiser’s Edge is a dynamic system, with data continually updated/overwritten; it captures the current situation and as such is unsuited for the extraction of accurate historical data. For example, an SOI athlete may be either “active” on the system or “deactivated”.
If an athlete initially registering with SOI in 2006 was “deactivated” for example, in the years 2009-2011, but re-engaged with SOI in 2012, interrogation of the database from 2012 onwards would give the impression that the athlete had been continuously active from 2006 onwards; i.e., there is no record of the previous deactivation. Records were transcribed to the Raiser’s Edge system only in recent years, and this resulted in a default date of 21/01/2005 being used as the initial registration date for athletes, volunteers etc., even if they had been affiliated with SOI for many years prior. Therefore, it is not possible to create an accurate picture of, for example, the pattern and number of years an athlete has been affiliated to SOI, or the historical growth of the organisation, for example, in terms of date of establishment of SOI clubs. Ideally, it would be useful to assess the weekly/annual amount of time spent training by SOI athletes. SOI clubs must register annually with central SOI and the application form requests information on the sport(s) offered, the training day, and time. However, the length of time of the training sessions is not requested, and what information is

gathered is entered in an open text “notes” field on The Raiser’s Edge, rendering it difficult to analyse.

8.3.3 Data on volunteer activities

Aim: To quantify the “in-kind” contribution of volunteers by examining the time in hours which volunteers donate to SOI and to estimate the value in monetary terms, as an indicator of returns generated by the organisation’s work processes.

Data: A limitation of the database maintained at SOI centrally was that the actual volunteer time donated is not recorded on the system for volunteers. Volunteers have a variety of roles in SOI, for example, fundraising, sports coaching, club volunteers, 1-day competition events volunteers, all-Ireland games volunteers, volunteers who tutor new volunteers, volunteers who provide administrative help to the central or regional offices. An individual volunteer may be labelled under multiple roles in The Raiser’s Edge system and is assigned “jobs” in a given year (active volunteer), but hours are not recorded. The professional qualifications or skills of the volunteers are not documented in the system. To ascertain the time provided by volunteers, we developed a short questionnaire to capture volunteer hours and athletes training hours at Community-Based Clubs (CBCs) nationally and distributed this via email to club coaches using SurveyMonkey (https://www.surveymonkey.com/).

Analysis: The data was entered automatically from SurveyMonkey into Microsoft Excel and was later analysed using the statistical package Stata®. In relation to the 4-year span of data required, figures were extracted from the SOI annual ”Reports and Financial Statements” to 31st December of each year, which are in the public domain.

8.4 Results

8.4.1 The organisation and structure of SOI.

Table 1. Change in number of athletes and volunteers by year (2009-13). Source: SOI annual year-end Reports and Financial Statements.

	Number of SOI athletes reported at year end.	Number of new athletes that year	No. of clubs at end of year	New clubs established that year	Volunteer pool	Active volunteers	New volunteers that year
2009	10,979	n/a	n/a	n/a	24,128	n/a	n/a
2010	10,646	834	409	18	25,961	n/a	n/a
2011	10,772	1,046	399	16	23,839	n/a	1,839
2012	10,834	985	398	17	24,334	7,233	1,104
2013	9,193	682	378	9	25,566	8,462	1,486
2014 (spring/summer)	9,361*	n/a	385**	7 to date	n/a	n/a	n/a
2014***	9,703	680	372	10	27,467	8,655	1,121

*Figure reported on SOI website (http://specialolympics.ie/) spring 2014.
**Figure based on data on clubs provided by SOI spring 2014.
*** The Reports and Financial Statements for the year ended 2014 did not become available until June 2015 and the figures extracted are provided largely for information only.

Each year, new athletes may register with SOI, and athletes may discontinue affiliation with SOI, new clubs may be established, or clubs may no longer be affiliated, new volunteers may register or current volunteers may be deactivated on the system. As noted previously, The Raiser's Edge system data describes only the current situation. The figures for each year in Table 1 above are those extracted at the time by SOI for their annual financial reports. It can be seen that the volunteer pool that SOI can draw on remains in the region of 24 – 26,000 people over the period 2010-2013 inclusive and that the number of affiliated clubs has not varied hugely over the period (ranging between 378-409). In general, it appears that describing the spring 2014 situation in relation to distributions of clubs, athletes, and active volunteers, would give a reasonable estimate of the situation for each of the prior four years. The number of SOI athletes registered at year end 2009-2012, ranged from 10,646 in 2010 to 10,979 in 2009 (a variation of no more than 3%). However, an apparently abrupt decrease in the number of registered SOI athletes between 2012 and 2013 (10,834 to 9,193) requires explanation. Athletes participating in SOI must register every 5 years, and the details of the clubs they are affiliated to and the sports they are participating in, are updated on the system at this time. However, in 2013, SOI completed a programme of deactivating on the system, those athletes who appeared on the system as active, but had not in fact been re-registered in the prior 5-year period. This culling of "ghost" athletes from the system is probably responsible for the majority of the drop in figures for registered athletes between 2012 and 2013. However, this means that the figures for the years prior to 2013 are likely overestimated. It is impossible to now assess exactly what the correct figures for active athletes in the years should have been, and it was judged simplest to merely subtract the differential between 2013 and 2012 figures viz. 1,641 from the number of athletes reported for each of the selected year, as a crude estimate of the figures. To give an estimate of the cost of running SOI Programmes per active athlete, it was judged preferable to have an estimate which underestimates the number of active athletes, rather than an overestimate. These revised figures are shown in Table 2.

Table 2. Revised estimate for active athlete figures in 2009-2014 cf. Table 1.

Year	Number of registered SOI athletes reported at year end.	**Revised estimate of number of registered athletes at year end**	No. of new athletes that year
2009	10,979	**9,338**	n/a
2010	10,646	**9,005**	834
2011	10,772	**9,131**	1,046
2012	10,834	**9,193**	985
2013	9,193	**9,193**	682

Spring 2014	9,361	**9,361**	n/a
End 2014	9,703	**9,703**	680

8.4.2 Range of SOI Clubs and sports offered.

As stated, in spring 2014, 385 clubs were affiliated to SOI throughout the island of Ireland, with 9,361 athletes participating in 15 sports offered by the clubs.

The SOI Sports. Fifteen SO sports are currently on offer in Ireland. These are: aquatics, athletics, badminton, basketball, bocce, bowling, equestrian sports, football, golf, gymnastics, kayaking, pitch & putt, table tennis, as well as the winter sports of floorball and alpine skiing. Also, many clubs offer the Motor Activities Training Programme (MATP) which is focused on the development of fundamental motor skills, and many run the Athletic Leadership Programme (ALP) designed to help athletes participate as leaders and ambassadors within SO and their own community. SOI clubs may offer athletes the opportunity to take part in a single sport (such as golf or swimming) or multiple sports, the latter being particularly common to service provider clubs. The table below shows the frequency with which individual sporting activities were offered to athletes by clubs in spring 2014. Aquatics and athletics are the most commonly provided activities, with floorball, kayaking and skiing the least common.

Table 3: Sporting activities provided by SOI clubs. Source: Data requested from and provided by SOI spring 2014.

Sport	Number of clubs providing this sport
Aquatics	169
Athletics	165
Tenpin Bowling	124
Bocce	107
Basketball	103
Football 5-a-side	97
MATP	84
Golf	83
Equestrian	69
Table Tennis	50
Badminton	42
Pitch and Putt	32
Gymnastics (Artistic)	23
Gymnastics (Rhythmic)	16
Football (11-a-side)	15
Kayaking	9
Floorball	7

Alpine Skiing	2

CBC to SP club ratio. Of the 385 clubs affiliated to SOI in spring 2014, 234 or 60.8% were Community-Based Clubs (CBC) and 151 or 39.2% were Service-Provider (SP) clubs. In the seven years since 2006, a shift has been observed from approximate division of clubs of 60% SP, 40% CBC to 40% SP, 60% CBC. This means that the economic burden of running SOI programmes has rapidly shifted from Service Providers to the local communities. The shift is presumably due to service providers, following the economic crash of 2008, finding they no longer have funding for running SOI programmes. Anecdotally, when a SP club stops running SOI programmes in a certain local area, it is not unusual to discover a community-based club being set up in the local area in the year or two following. Ireland appears to be unique in the high proportion of SOI community-based clubs providing athletes with the services.

Table 4: Breakdown of ratio of Community Based clubs CBC) to Service Provider clubs (SP) 2014 cf. 2006. Data requested from and supplied by SOI.

	CBC	**SP**	**Total**	**% CBC**
2006	172	226	398	43%
2014	234	151	385	61%

8.4.3 Number of registered SOI clubs per region and year.

It can be seen from the table below that Ulster has the highest number of SOI-affiliated clubs, that the proportion of community-based clubs (CBC) is particularly high in Ulster, Munster and the Eastern region, but that the Leinster region clubs retain the 2006 overall pattern of 60% SP: 40% CBC.

Table 5: Regional breakdown of the number of clubs and proportion of the total. Data requested from and supplied by SOI April 2014.

Region	Total clubs	CBC	SP
Connaught	80	43 (53.8%)	37 (46.3%)
Eastern	85	59 (69.4%)	26 (30.6%)
Leinster	64	25 (39.1%)	39 (60.9%)
Munster	64	45 (70.3%)	19 (29.7%)
Ulster	92	62 (67.4%)	30 (32.6%)
Total	**385**	**234**	**151**

8.4.4 Regional breakdown of athlete registration.

An athlete may be affiliated to more than one SOI club, so that although in spring 2014 there were 9,361 individual athletes registered on the SOI database, there was a total of 12,183 affiliations between athletes and clubs. It can be seen from the table below that, in these terms, the Eastern region is the most active region with 3,057 club memberships, and Connaught is the least active region at 1,829 club memberships.

Table 6: Total number of *registered* athletes per region. Source: club data supplied by SOI April 2014.

Region	Total athlete registrations
Connaught	1,829
Eastern	3,057
Leinster	1,898
Munster	2,756
Ulster	2,643
Total	**12,183**

The 385 SOI clubs had memberships ranging from 2 athletes to 215 athletes, with 26 registered members the median value. It is apparent from the table below that a considerable range exists in terms of club memberships.

Table 7: Number of registered athletes per club. Source: Data requested from and supplied by SOI April 2014.

Number of athletes registered	All clubs (385)	CBC (234)	SP (151)
≥100	15	8	7
50-99	50	37	13
30-49	68	51	17
20-29	89	60	29
10-19	104	57	47
<10	59	21	38

Full data on 9,216 athletes in spring 2014 revealed the following breakdown in relation to SOI region and to which of the 32 counties in Ireland each athlete cited as their “preferred county”. Co. Dublin and Co. Cork combined comprised 29% of all the athletes, with the fewest athletes identifying with Leitrim or Longford.

Table 8: Breakdown of 9,216 athletes by SOI region. Source: Data requested from and supplied by SOI April 2014.

SOI Region	Number of athletes registered
Munster	2,265
Eastern	2,223

Ulster	1,958
Leinster	1,478
Connaught	1,292

Table 9: Breakdown of 9,215 of 9216 athletes by Irish county. Source: Data requested from and supplied by SOI April 2014.

County	Number of athletes identifying this county as preferred
Co. Dublin	1,789
Co. Cork	897
Co. Antrim	499
Co. Galway	417
Co. Kildare	390
Co. Limerick	369
Co. Waterford	358
Co. Donegal	348
Co. Down	347
Co. Tipperary	311
Co. Mayo	297
Co. Wexford	295
Co. Wicklow	284
Co. Meath	256
Co. Derry	213
Co. Sligo	197
Co. Kilkenny	190
Co. Westmeath	175
Co. Tyrone	174
Co. Carlow	160
Co. Kerry	159
Co. Clare	157
Co. Louth	146
Co. Armagh	145
Co. Offaly	135
Co. Roscommon	103
Co. Cavan	88
Co. Monaghan	83
Co. Fermanagh	73
Co. Laois	64
Co. Leitrim	49
Co. Longford	47

8.4.5 Athlete profiles.

For the 9,216 athletes for whom full data was provided by SOI, the gender divide was noticeable. Females accounted for 3,604 of the athletes or 39%, while the remaining 5,612 were male. The average age of the SOI athlete was 30, with ages ranging from 1 to 84 recorded. The average for males was 29, slightly younger than the average age of 32 for females.

8.4.6 Direct Costs of SOI

Introduction.

Consultation with SOI revealed that there are no typical financial years for the organisation, particularly because SOI continually follows the international 4-year athlete advancement cycle, as described previously. The different activities for each year of the cycle have very different expenditures attached to them; this means that the idea of a "typical financial year" does not exist for SOI.

Rationale:

In order to ensure capturing all the fluctuations in finances over the 4-year cycle, complete financial records for SOI for the most recent four years were requested and supplied. These years were 2010-2013 inclusive. These years do not represent a Year 1 to Year 4 progression of a cycle, but rather Years 3 and 4 of one cycle (2008-2011) and Years 1 and 2 of the following cycle (2012-2014). This is illustrated in the table below in which the relevant years are outlined in bold.

Table 10: Events over the four year cycle. Source: www.specialolympics.ie

Year 1 (Area events)	Year 2 (Regional events + World Winter Games)	Year 3 (All-Ireland games)	Year 4 (World Summer Games)
2004	2005	2006	2007
2008	2009	**2010 (Limerick)**	**2011 (Athens)**
2012	**2013 (S. Korea)**	2014	2015

Illustration of how the four years of finances investigated (2010 – 2013, presented in bold font) fall into the SO Ireland 4-year advancement cycle.

A typical 4-year cycle?

In fact, it would be difficult to describe a "typical" 4 year cycle. The 2004-2007 cycle, which followed the 2003 World Summer Olympics Games being held in Ireland for the first time, represented a period of rapid growth for the organisation, while the worldwide economic recession took hold during the 2008-2011 cycle. The most expensive year of the 4-year cycle in terms of total SOI expenditure is invariably Year 3, when the all-Ireland games are held. However, it is worth noting that the 2010 games had already been planned and budgeted for prior to the recession, and, of necessity, many steps were taken to ensure those planned for 2014 would be significantly less expensive. Key events occurring during the four years 2010-2013 inclusive are listed below. The year prior (2009) and the year after (2014) are also listed for comparative purposes.

Table 11: Key Events occurring in the years 2009 – 2015 inclusive. Source: www.specialolympics.ie

Year	**SOI cycle year**	**Key events**
2009	Year 2 (regional + world winter games)	8 SOI athletes travelled to compete in the World Winter Games, in Idaho, USA. They were accompanied by a team of 35 volunteers.
2010	**Year 3 (all-Ireland games)**	1,900 athletes competed in the all-Ireland games in Limerick. They were supported by 650 coaches, 3,500 volunteers, 9,000 supporters/family members. Also, 35 athletes competed at the 2010 European Games in Poland.
2011	**Year 4 (World Summer Games)**	126 SOI athletes competed in the World Summer Games in Athens; 186 volunteers accompanied them.
2012	**Year 1 (local area competitions)**	224 competition events held across the island of Ireland.
2013	**Year 2 (regional + winter world games)**	14 athletes competed in the world winter games in South Korea (8 volunteers also travelled). 4,100 athletes participated in 67 regional advancement competitions.
2014	Year 3 (all-Ireland games)	All-Ireland games in Limerick in June 2014 (participation of ~1,500 athletes)
2015	Year 4 (World Summer Games)	Held in Los Angeles, U.S.A end July 2015.

SOI keeps detailed quarterly financial records which show the cumulative expenditure for a) Central Office b) the five Regional Offices and c) games if applicable. The Central SOI programme/office is divided into six departments each with its own payroll. These six departments are 1. Business & Administration, 2. Executive Office, 3. Finance, 4. Marketing, Public Relations & Communications, 5. Sports, and 6. Support Programmes. In addition, the central programme accounts also include expenditure on “Short-term funded projects” such as “Women in Sport programme”. The “Sports” department expenses incorporate expenditure related to games and the “Support Programmes” expenses include those for the Volunteer Programme and the Athlete Leadership programme. Expenditure for each of the 5 Regional Offices is also broken down, using categories such as games/events, athlete recruitment programmes, office rent and service charges. There are detailed accounts, if applicable for that year, for expenditure on games including, for example, the cost of ceremonies and venue hire. Similarly, income is reported for both the central programme and the regional offices, as well as a detailed breakdown of all fundraising and sponsorship. These accounts were made available by SOI for the selected years 2010-2013. However, these cumulative reports which separate accounts for the central office and the regional offices are kept only until September or October of a given year, while official annual SOI annual reports to 31 December of a given year combine the yearly expenditure of the central office and the regional offices under specific categories, (likewise combining income from the central office and the regional offices). From 2011 onwards, total expenditure for SOI in these annual reports is divided into six categories, viz. 1. Sports Programmes, 2. Games and Events, 3. Support Programmes, 4. Governance, 5. Advocacy and 6. Fundraising. These annual reports for the selected years 2010-2014 are in the public domain and were also provided for analysis.

8.4.7 Overview of finances of SOI 2010-2013.

Table 12 provides a brief overview of the finances of SOI in the selected years 2010-2013, with 2009 figures also given for comparison. As expected, the year with the greatest expenditure (close to 8 million euro) is 2010, when the all-Ireland games were held. In the years following, total expenditure has been in the region of 5.5 – 5.8 million euro, highest during 2011 when attendance at the World Summer games took place. 2013 was Year 2 in the SO cycle (regional games) as was 2009. It is apparent that expenditure has been cut from 6.5 million euro to 5.6 million euro, a reduction of close to 14% expenditure for the same cycle year, with 2009 representing a pre-recession year and 2013 a post-recession year. It is also apparent that from 2010 to 2013 there has been a dramatic drop in income for SOI, decreasing from 7.7 million euro to 4.5 million euro, a drop of approximately 42%. This will be discussed in more detail below, but the result is that, despite efforts to cut expenditure in the years since 2010, for the combined years 2012 and 2013, there has been a shortfall between SOI expenditure and income of 2 million euro, about 18% of the combined expenditure for those two years.

Table 12: Income, expenditure and difference over the four SOI year competition advancement cycle. Source: Reports and Financial Statements SOI.

		Total expenditure (€000)	Total Income (€000)	Difference total income cf. total expenditure (€000)
Year 2	2009	6,472	7,289	817
Year 3	**2010**	7,839	7,739	-100
Year 4	**2011**	5,815	5,934	119
Year 1	**2012**	5,692	4,752	-940
Year 2	**2013**	5,584	4,478	-1,106

Table 13 shows the 2010-2013 breakdown of total expenditure across the six programmes: 1. Sports Programmes, 2. Games and Events, 3. Support Programmes, 4. Governance, 5. Advocacy and 6. Fundraising. Generally. less than a third of the annual expenditure is spent on Governance, Advocacy and Fundraising combined, with the vast majority being spent on the Sports Programmes, the Support Programmes, and to a lesser extent, the Games and Events. Expenditure on Support Programmes was consistent over the 4 years at about 1.4 million euro. Expenditure on Sports Programmes rose somewhat over the 4 years from about 1.7 million to 1.9 million euro. For Games and Events, it is clear that considerable additional expenditure was required in 2010 to run the 2010 all-Ireland games in Limerick, and this more than accounts for the rise in total expenditure to close to 8 million euro in that year. It should be noted that total payroll and operational costs for different departments (e.g. Executive Office, Finance) are distributed according to set ratios across all six expenditure categories, so the distributions are not entirely clear cut.

Table 13: Breakdown of total expenditure by activities. Source: Reports and Financial Statements SOI.

Year in 4-year Cycle	Year	Proportion of total expenditure on specific activities							
		Total expenditure (€000)	Sports Programmes (€000)	Games & Events (€000)	Support Programmes (€000)	Governance (€000)	Advocacy (€000)	Fundraising (€000)	Restricted reserve (€000)
2	2009	6,472	n/a	n/a	n/a	n/a	n/a	n/a	n/a
3	**2010**	**7,839**	**22%**	**42%**	**18%**	**5%**	**4%**	**10%**	**n/a**
4	**2011**	**5,815**	**29%**	**14%**	**25%**	**7%**	**5%**	**20%**	**n/a**
1	**2012**	**5,692**	**33%**	**10%**	**26%**	**8%**	**5%**	**17%**	**1%**
2	**2013**	**5,584**	**35%**	**10%**	**26%**	**9%**	**6%**	**15%**	**1%**

As might be expected, employment costs account for a large percentage of total annual expenditure. The average number of full-time-equivalent (fte) SOI employees ranged from 84 to 88 over the four years 2010-2013, with employment costs accounting for about 59%-63% of total expenditure for the years 2011-2013. Employment costs were similar in 2010, but accounted for a significantly lower percentage of the total 2010 expenditure, which in this year included a spend of 2.8 million euro on games alone.

8.4.8 Sources of SOI revenue

Annual income for SOI is almost entirely based on a) grants and b) fundraising, sponsorship and donations. In relation to grants, the core funder for SOI is the Irish Sports Council. As detailed above, SOI expends considerable monies annually in fundraising campaigns, as this is vital to continued income. It has been pointed out that in the past few years SOI has endured a large deficit between expenditure and income, which is not explained by change in expenditure (which has been declining).

Table 14: Sources of revenue supporting SOI. Source: Annual SOI Reports and Financial Statements

		Total Income (€000)	**Income via fundraising, sponsorship & donations (€000)**	**Investment Income**	**Games Income**	**Regional Office Income**	**Other Income**	**Total Grant income (€000)**	Irish Sports Council Grant income (€000)	Sports Council of Northern Ireland grant (€000)	Other Grants
Year 2	2009	**7,289**	**2,753**	**227**		**1,247**	**100**	**2,962**	2,622	n/a	340
Year 3	2010	**7,739**	**2,144**	**357**	**625**	**1,785**	**207**	**2,621**	2,308	n/a	313
Year 4	2011	**5,934**	**2,664**	**340**			**178**	**2,752**	1,765	405	582
Year 1	2012	**4,752**	**1,798**	**467**			**120**	**2,367**	1,200	716	451
Year 2	2013	**4,478**	**1,774**	**329**			**137**	**2,238**	1,206	700	332
Average	**2009-13**	**6,038**									

The table above shows that there has been a dramatic drop in total income from 2010-2013. For 2009 (Year 2 of cycle), total income was 7.3 million euro, cf. 2013 (also Year 2 of cycle) for which total income was 4.5 million euro, a drop of 38.6% in funds. Total grant income was 24% lower in 2013 compared to 2009, a factor hugely influenced by cuts of more than 50% in grant income from the core funder, the Irish Sports Council (ISC). The table below illustrates how, from 2008 onwards, the ISC grant cuts have meant that this core funding supports a decreasing percentage of SOI's total expenditure, which is itself declining. It is noted in the table above, however, that in 2011 the Northern Ireland Executive signed up to provide funding for the Northern Ireland element of SOI programmes until 2015, offsetting the funding loss from ISC to some degree. It can also be clearly seen from the table above that SOI income from fundraising, sponsorship and donations has seen a general decline since the economic crisis. For example, one of SOI's key fundraising events is the Annual Collection Day; in 2013 SOI reported that this yielded approximately €485,000 compared to approximately €589,000 in 2012, a decrease of 17.6%

Table 15. Decline in annual Irish Sports Council (ISC) grant, actual and as a percentage of total SOI expenditure/ costs. Source: Annual SOI "Reports and Financial Statements"

Financial Year	ISC Grant €'000	ISC funding as % of Costs
2007	2,988	45%
2008	2,925	49%
2009	2,622	41%
2010	2,308	29%
2011	1,765	30%
2012	1,200	21%
2013	1,206	22%

* Included in the 2011 ISC grant above is an additional award of €265k for the 2011 World Summer Games in Athens, Greece.

It was apparent that SOI faced a very serious financial situation in 2014. Major reductions in core grant funding and in funds raised over the past several years, had led to a large deficit between expenditure and income for the years 2012 and 2013, a reduction in expenditure notwithstanding. SOI has met the shortfall of approximately 2 million euro for the years 2012 and 2013 by using its reserve funds. These funds are finite, however, and if annual shortfalls of approximately 1 million euro were to continue, SOI would be unsustainable as an organisation within a decade. To this end, SOI had little option but to make redundancies in its staff to contain expenditure, and it is noted that the number of full-time staff reported at the end of the 2014 financial report is 65, compared with 75 at the end of 2013. Most redundancies occurred in autumn of 2014, so to some extent, the remuneration savings are not reflected in the end of 2014 accounts. A 2014 saving of €441K in staff costs cf. 2013 is largely offset by 2014 restructuring costs of €312K. Total expenditure in 2014 was substantially greater than in 2013 (€6,319K cf. €5,584K) but this is largely explained by 2014 expenditure on the all-Ireland games (an extra €984K cf. 2013). However, it is interesting to note that at the end of 2014, the overall deficit was €272,658 cf. €1,075,469 in 2013. It remains to be seen whether the >10% reduction in staff in 2014 will adversely affect the services that SOI provides in the future, especially in light of significantly increased numbers of registered athletes in the same year (9,703 in 2014 cf. 9,193 in 2013).

8.4.9 SOI expenditure.

It would be useful to consider the total annual expenditure by SOI in terms of the number of athletes taking part in training every year. As presented earlier, it would appear that the reported number of athletes was overestimated in the years 2009 – 2012, and a more conservative revised estimate of the numbers was presented (Extracts from Table 2 reproduced below as Table 16).

Table 16. Number of registered SOI athletes. See Table 2.

Year	Number of registered SOI athletes reported at year end	Revised estimate of number of registered athletes at year end
2009	10,979	**9,338**
2010	10,646	**9,005**
2011	10,772	**9,131**
2012	10,834	**9,193**
2013	9,193	**9,193**
Spring 2014	9,361	**9,361**
End 2014	9,703	**9,703**

As might be expected, expenditure per head is considerably higher in the cycle year of greatest expenditure, when the all-Ireland games are held (see Table 17). This equates to €871 per head in that year, 2010. For the subsequent years, 2011-2013, the expenditure per head remains in the range €607-€637. It is also worth noting that for comparable years 2009 and 2013, both year 2 of the advancement cycle, the cost per head appears to have dropped from close to €700 per head annually, to close to €600 euro per head, an apparent saving of 17% expenditure per training athlete post-recession cf. pre-recession.

The entire structure of the SOI organisation in the years 2011-2013 was run for the annual sum of approximately €620 per registered athlete. However, recent large shortfalls between SOI income and expenditure imply that, annually, a further income of approximately €120 per registered athlete must be found in order for SOI to make ends meet and continue to exist as an organisation.

Additional data received in 2015, based on end 2014 SOI Reports and Financial Statements, reveal that the cost per registered athlete was €650. This should be compared to the €871 per head in 2010, a comparable cycle year, in which all-Ireland games were held. Due to the considerable drop in expenditure deficit in 2014 combined with the increase in athlete numbers noted above, the deficit per registered athlete dropped from €120 per head to €28 per head. It is impossible to predict from 2014 data alone whether this significant drop in expenditure deficit per registered athlete will be maintained in the coming years.

Table 17. Mean estimated cost per registered athlete

Cycle Year	Calendar Year	Total expenditure €	Expenditure per reported registered athlete €	**Expenditure per estimated registered athlete €**	Shortfall per estimated registered athlete €
Year 2 (regional)	2009	6,471,698	589	**693**	n/a
Year 3 (all-Ireland games)	**2010**	7,839,330	736	**871**	n/a
Year 4 (world games)	**2011**	5,815,277	540	**637**	n/a
Year 1 (local area)	**2012**	5,692,243	525	**619**	-102
Year 2 (regional)	**2013**	5,584,430	607	**607**	-120

8.4.10 Economic evaluation of the implications of SOI

Estimation of athlete training time provided by SOI

A primary benefit of SOI as an organisation can be expressed as the amount of training time it provides to athletes annually. By extension, each hour of training will confer some benefit to the physical, mental and emotional well-being of both athletes and their families.

To assess the current level of training time produced by SOI across Ireland, all Community-Based-Clubs were invited to respond to an online survey (n=224). A total of 91 clubs responded with useful information on this subject (response rate 41%).

Most commonly, SOI clubs reported servicing a ‘mixed’ rural/urban area (n=57), followed by ‘urban’ area (n=24), and the least common were clubs that reported covering a ‘rural’ area (n=9).

Of the 91 respondents, 18 stated that their club was based in Co. Dublin, 8 in Co. Galway, 6 in Co. Cork, 6 in Co. Kildare, 4 in Co. Waterford and 3 or fewer in a variety of other counties throughout Ireland. Asked how many weeks per year the club provided training, the most common response was in the range 36-40 weeks (36 of 91), but answers ranged from 20 weeks to 50 weeks.

Further data from the survey shows the number of athletes training by geographic coverage of club. Of the 91 clubs that completed the survey, 80 provided information on the geographic location of their club as well as the number of training athletes.

Table 18: Number of athletes training by geographic coverage of club [Source: SOI Club Survey, 2015]

	Number of athletes attend your club for training in a typical week? (Divided by type of area)				
Geographic coverage	**Mean**	**sd**	**n**	**Median**	**Interquartile range**
Mixed	34.75	32.98	48	24	18 - 39
Rural	14.71	5.59	7	16	7 - 20
Urban	26.46	17.15	24	20	15 - 38
Total	**30.25**	**27.866**	**80**	**20**	**15 - 36**

Of 80 respondents who directly answered the question on the number of athletes that attend in a typical week, answers varied between 6 athletes and 200 athletes. The most common number of athletes (median) reported was 20 athletes, with a mean 30.25 athletes. Clubs servicing a ‘mixed’ rural/urban area had the largest number of training athletes (Mean: 34.75), followed by ‘urban’ (Mean: 26.46), while ‘rural’ club, on average, tended to have the smallest number of athletes (Mean: 14.71).

To further understand training within the clubs, respondents were asked to report how much the ‘typical athlete trains each week’; Table 19 reports statistics on the reported average training across varying geographical locations.

Table19: Training time per week (minutes) by geographic coverage of club [Source: SOI Club Survey, 2015]

	Training by the typical athlete per week (minutes) (Divided by type of area)				
Geographic coverage	**Mean**	**sd**	**n**	**Median**	**Interquartile range**
Mixed	90	39	50	65	60 - 120
Rural	95	48	6	75	60 - 120
Urban	96	41	24	90	60 - 120
Total	**92**	**40**	**80**	**83**	**60 - 120**

On average, clubs tended to provide 92 minutes of training per week and this did not vary by the geographical location. At the extremes, the length of time a typical athlete trained per week ranged from 30 minutes to 3.5 hours.

The survey undertaken in 2015 was further utilised to calculate for each club the average total number of athlete training hours per club each year. A total of 69 clubs provided information on both ‘length of time a typical athlete trained per week’ and ‘the number of weeks per year trained by the club’. Table 20 reports: 1. the average number of hours of training provided to the average athlete; 2. the average number of hours of training provided to all athletes in the average club (multiplied by the reported number of athletes per club) and; the estimated total number of hours provided by SOI across Ireland (based on the number of registered clubs in 2014, n=234).

Table 20: Average number of hours of training provided a. per SOI athlete, b. per club, c. estimated across all SOI Clubs (n=234)

Average training hours:	Mean	sd	Min	Max	n
per athlete per year	61.58	32.17	18	156	69
per club per year	2,437.3	3,852.18	108	24600	65
SOI Clubs (n=234)	570,327.3	901,411.2	25,272	5,756,400	

Out of the 91 clubs, 69 clubs had sufficient information to estimate the mean number of hours per year of training to the average athlete (61.58 hours). Of these, 65 had also indicated their number of training athletes allowing the total number of hours of training per average club to be estimated (2437.3 hours per year).

The number of Community-Based Clubs (CBCs) registered in 2014 with SOI was 234. Assuming that the average number of hours provided by the average SOI club is captured from survey results, this would suggests that across Ireland SOI is responsible for delivering a total of **570,327 hours** (min-max: 25,272 – 5,756,400) of training per year in CBCs alone; these estimates are used for total value of SOI activities using units costs (Table 21) and presenting this as a total monetary values (Table 22). Athlete training hours for Service Provider SOI clubs has not been estimated.

Various economic perspectives may be applied to indicate an economic value of the total number of hours of training. Table 21 indicates the value of an hour of training with SOI from the perspective of the individual (the athlete), the productivity loss of a family (e.g. wages foregone to providing care) and the proxy-good value of an hour of care to health and social care.

Table 21: Relevant values to an hour of training with SOI.

Perspective	Valuation (€/hours)	Valuation method	Source
Individual	7.30	Leisure time	Common Appraisal Framework for Transport Projects and Programmes, p.41
Informal Care	8.65 18.56	Minimum wage Average wage	Citizens Information CSO 2015
Health and Social Care	33.62	Proxy good: Care assistant (intellectual disability agencies)	Trepel 2011: 'Care assistant (intellectual disability agencies)', p. 495

Applying various perspectives to assign values to the training provided by SOI, benefits of training are expressed in monetary values to the various stakeholders (i.e. individual, informal carers (i.e. the earning potential foregone due to providing care) or Health and Social Care). Table 22 reports the mean estimates with 95% confidence intervals across SOI (based on the survey responses of the 65 out of 234 clubs).

Table22: Estimated total value of the athlete training provided by SOI.

Perspective	Mean (€)	[95% Conf. Interval]			n
Individual	4,163,389	2,532,870	-	5,793,908	65
Informal Care	4,933,331	3,001,278	-	6,865,384	65
Formal care	19,200,000	11,700,000	-	26,700,000	65
Societal perspective*	**7,588,775**	**4,616,764**	**-**	**10,600,000**	**65**

* Empirically, an assumption of the ratio of informal care to formal care was required to estimate the value from a societal perspective. Full societal perspective assumes the ratio of informal care to formal care was equal (50:50) between the two sectors. This is applied in calculating cost at each for the individual level and the figure provides Mean (955 CI) estimates across all individuals.

Across all SOI clubs (n=234 clubs), it is estimated that a total of **570,327** athlete training hours per annum are produced (free-of-charge to the athlete). The estimated value to the athlete in terms of their leisure time is €4.16 million/year. The potential value of the hours of informal care displaced by SOI training is €4.93 million/year. The opportunity cost of all hours provided by SOI had they been provided by a formal care provider (e.g. HSE: 'Care assistant (intellectual disability agencies)') would cost the Irish Health Service Executive (HSE) €19.2 million/year). At a societal level, it is estimated that the athlete training is worth **€7.59 million/year (95% CI: €4,62m. to €10,60m)**.

8.4.11 The value of volunteer time donated to SOI.

SOI have c. 25,000 registered volunteers and about 8,000 are active at any one time; however, volunteer activities within clubs are not currently recorded by SOI at a central level.

Table 23 provides survey responses to the question '*How many hours does a typical volunteer/coach give each week?*', divided by the size of the SOI Club in terms of number of athletes. On aggregate, for 70 SOI Clubs, an SOI volunteer provides an average of 117 minutes per week of volunteer time. As club size increases, so does mean volunteer time per week. For example, the volunteer time in clubs with less than 40 athletes is 104 minutes per week, whereas in clubs with 160 to 200 members, the average volunteer provides 146 minutes per week.

Table 23: Time volunteered (minutes) per week by club size [Source: SOI Club Survey, 2015]

		Weekly Time Volunteering (minutes) (Divided by club size)			
Number of athletes	**Number of clubs within the size range**	**Mean**	**sd**	**Median**	**Interquartile range**
<20	13	104	38	120	60 - 120
20-79	17	114	53	105	69 - 120
80-119	13	108	47	90	60 - 120

120-159	13	113	37	120	90 - 120
160-200	14	146	37	150	120 - 180
Total	70	117	45	120	90 - 150

Clubs were also asked '*How many people, in total, volunteer or coach at your club in a typical week*?' and the results are reported in Table 24 (again subdivided by the size of the SOI Club). The national average number of reported volunteers is 9.93 per club and the number of volunteers increases with increasing club size (from an average of 5.27 volunteers in a club with less than 20 members to an average of 15 volunteers in a club with 160-200 members).

Table 24: Number of volunteers by club size [Source: SOI Club Survey, 2015]

Number of athletes	**Number of clubs within the size range**	**Number of Volunteers (Divided by club size)**			
		Mean	**sd**	**Median**	**Interquartile range**
<20	15	5.27	2.22	5	3 - 7
20-79	17	7.85	4.49	7	6 - 8
80-119	14	7.43	3.99	6.5	5 - 11
120--159	13	14.46	6.92	12	8 - 20
160-200	16	15.00	8.88	12	10 - 18
Total	**75**	**9.93**	**6.90**	**8**	**6 - 12**

Survey respondents were also asked to specify details on individual weekly sessions of training (see Table 25). The data collected in this section asked for extensive information and had a low response rate (n=41). Based on the limited information provided, it is suggested that the largest (160-200 athletes) and then the smallest clubs (i.e. <20 athletes) have the highest number of weekly sessions, whilst the mean number of sessions reduces for those with between 20 and 159 members.

Table 25: Number of weekly club sessions by club size [Source: SOI Club Survey, 2015]

Number of athletes	**Number of clubs within the size range**	**Number of Sessions per week (Divided by Club Size)**			
		Mean	**sd**	**Median**	**Interquartile range**
<20	7	3.29	5.62	1	1 - 2
20-79	7	1.29	0.49	1	1 - 2
80-119	7	1.71	0.76	2	1 - 2
120--159	6	2.33	2.42	1	1 - 3
160-200	14	4.21	3.12	3.5	2 - 5
Total	**41**	**2.85**	**3.18**	**2**	**1 - 3**

Survey data was exploited to estimate a national average of volunteer hours donated by each volunteer. Based on available responses indicating the ‘*number of weeks per year of training provided’* and the ‘*time volunteered (minutes) per week'*, it is found that the average volunteer provides 76 hours per year (95% CI: 68 to 84 hours/year). Scaling this donation by the reported number of volunteers per club, we can estimate the average number of volunteer hours received per club as 782 hours per club per year (95% CI: 607 to 956 hours/year). This would suggest SOI are responsible for providing **182,988 hours** of volunteering per year.

To indicate the monetary value of volunteer time donated to SOI clubs, the 2015 Irish minimum wage (€8.65 hour) was applied for each reported volunteer hour over a year. Table 26 reports the average monetary value of volunteer time donated at the club level and disaggregates these values by club size. The average value of donated volunteer time per club is **€6,795 per year.**

Table 26: Opportunity cost of volunteering by club (divided by size) [Source: SOI Club Survey, 2015]

		Number of Sessions per week (Divided by Club Size)			
Number of athletes	**Number of clubs within the size range**	**Mean (€)**	**sd**	**Median**	**Interquartile range**
<20	10	2,405	1,577	1,946	1,730 - 2,422
20-79	15	4,734	3,155	3,460	1,868 - 7,197
80-119	13	4,529	3,321	3,598	2,699 - 4,775
120--159	8	9,294	5,205	9,221	4,429 - 14,186
160-200	13	13,278	7,314	9,550	8,304 - 17,542
Total	**59**	**6,795**	**5,938**	**4,775**	**2,422 - 9,342**

The SOI register indicated that in 2014 there was a total of 234 clubs in the community. Table 27 indicates the total value of volunteer time produced across all clubs in Ireland and provide the societal value of athlete training, representing an estimate of the notional value of the training delivered for athletes from the perspective of the service provider.

Table 27: Estimates of the value of volunteering for SOI per annum (Opportunity cost per hour either based on minimum wage or Average industrial wage).

For SOI Clubs, value of volunteering based on:	**Mean**	**[95% Conf. Interval]**
Minimum wage	€ 1,581,942	€ 1,228,190 - € 1,935,694
Average wage	€ 3,394,463	€ 2,635,397 - € 4,153,530

Based on the minimum wage rate, the value of volunteer time produced by SOI is **€1.58 million per annum (95% CI: €1.23m to €1.94m).**

However, the valuation of volunteer time based on minimum wage may not accurately reflect true opportunity cost to the volunteer. To apply an alternative valuation would be to apply the *average wage rate* of €18.56/hour[1] (CSO 2015). This would then increase the estimated value of the national volunteer time donation to **€3.39m per year (95% CI: €2.64m to €4.15m)**.

8.4.12 The Club-level Finances of Community-Based-Clubs

In 2014, SOI had 234 registered Community-Based-Clubs (CBC). These clubs were self-financing, and their club finances are not recorded by central SOI. It was of interest to get a measure of flow of club finances in their local communities and accordingly, CBCs were invited to provide information on their finances through a survey (available from SOI) developed by the research team (the survey was administered by SurveyMonkey to club treasurers). Table 28 summarises the income and expenditure as reported by club treasurers surveyed. The survey was completed by 57 clubs, of which only 28 reported their income (average annual income per club was €5,874) and 20 reported their expenditure (average annual expenditure per club was €7,175). Comparing the difference in income and expenditure between the 20 clubs who reported both, on average they appear to keep their budget balanced.

Table 28: Summary of reported club-level finances (income, expenditure & difference). [Source: SOI Club Survey, 2015]

	Reported Finances by Club (Euros*).				
Reported club finances	**Mean**	**sd**	**n**	**Median**	**Interquartile range**
Income	5,874	11,640	28	1,400	0 - 7,458
Expenditure	7,175	12,341	20	2,802	300 - 7,326
Difference (Inc -Exp)	**-147**	**4,779**	**20**	**0**	**-293 - 572**

* Clubs in Northern Ireland report finances in GBP. To summarise finances across the Island of Ireland, these are converted to Euros (based on average exchange rate: 0.7169 between June 2013- June 2014)

The income reported by the clubs provides an indication of the fundraising. Assuming that the limited sample provides a representative indication of the fundraising of the average club this data suggest that the national fund-raising of community clubs is €1,374,516.

Club treasurers were asked to report their club rents, insurance and fees. Table 29 summarises the responses provided by clubs.

Table 29: Summary of reported club-level outgoings (rents, insurance and fees). [Source: SOI Club Survey, 2015]

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[1] €696.03 per week and assuming 37.5 hours per week

	Reported Finances by Club (Euros*).				
Reported items	Mean	sd	n	Median	Interquartile range
Rents	1,721	2,801	15	1,000	25 - 1,696
Insurance	78	211	8	0	0 - 13
Fees payable	719	1,144	15	180	65 - 1,000

* Clubs in Northern Ireland report finances in GBP. To summarise finances across the Island of Ireland, these are converted to Euros (based on average exchange rate: 0.7169 between June 2013- June 2014)

Out of the 57 clubs who completed the survey, only a small number were able to report any information on rents (26%), insurance (14%) and fees payable (26%) For clubs who reported, rent would appear to be the main expense (median: €1,000), followed by fees payable (median: €180) and insurance (median: Nil).

8.4.13 Cost Benefit ratio

The analysis of SOI finances has provided a detailed indication of the cost of running SOI per year. To indicate the benefits of SOI, surveys of Clubs and Treasurers have provided information to indicate the value of outputs produced by SOI clubs; specifically the value of athlete training, volunteering and funds raised in the community.

Comparing the average expenditure of SOI to the benefits (valued in monetary terms) provides the basis for a 'decision rules' to indicate whether SOI represents value for money. The Net Present Value (NPV) is calculated by subtracting the present cost from the present benefit and, conventionally, a positive net present value would be considered for value for money.

Table 30 summarises the *Present Cost* (as indicated by the average total expenditure of SOI between 2009-13) and the *Present Benefits* (which is the sum of the value of athlete training, volunteering donated and funds raised in the community). The Net Present Value (Present Cost + Present Benefits) is €4,507,233 for the SOI organisation, which would suggest that very substantial value is gained from the current operations.

Table 30: Net present value

Present Cost	Value (€)
Average total expenditure (2009-13)	**- 6,038,000**
Present Benefits	
Societal value of athlete training	7,588,775
Value of volunteering	1,581,942
Funds raised by clubs	1,374,516
Total	**10,545,233**
Net present value	**4,507,233**

* Footnote: value of volunteering is the estimate based on Minimum wage (Table 27).

8.5 Summary of Key Findings

SOI programmes supports in the region of 380 SOI clubs and 9,000 registered athletes throughout the island of Ireland. Approximately 25,000 volunteers are registered with SOI, of which about 8,000 are active annually. In the years 2011-2013, the SOI organisation was run for the modest annual sum of approximately €620 per registered athlete. On average the SOI operations cost **€6,038,000 per annum.**

From 2010 to 2013 there has been a dramatic drop, approximately 42%, in income for SOI, a decrease in funding from the Irish Sports Council being a major factor in this. In 2012 and 2013, SOI has had a deficit of approximately €1,000,000 per year, meaning a further income of approximately €120 per registered athlete was required to sustain the organisation.

To reduce expenditure, SOI made substantial redundancies in 2014; the deficit between expenditure and income was substantially lower in that year, but it is too soon to predict the impact of this restructuring on savings or on impact to services in the coming years.

In the 7 years since 2006, when 60% of SOI clubs were through Service Providers, there has been a shift to 60% of SOI clubs being Community-Based-Clubs (CBCs). Such CBCs are almost entirely self-funding, the burden falling on the local community.

It is estimated that the 234 Community-Based-Clubs provide an average total of **570,327 hours** of training per year throughout the island of Ireland. This figure does not include training hours in Service Provider Clubs. The value to society of the training provided by SOI (in terms of value to individual, family and health and social care) is **€7.59 million/year (95% CI: €4,62m. to €10,60m)**.

It is estimated that club volunteers are providing the 234 CBCs with a total of **182,988 hours** of volunteering per annum throughout the island of Ireland. A conservative valuation of the volunteer time (using minimum wage) indicates that the annual value of volunteering for SOI is **€1.58 million per annum (95% CI: €1.23m to €1.94m).**

Furthermore, CBCs (to support their club activities) are estimated to fundraise an estimated **€1,374,516** across the 234 clubs.

The results of these analyses suggest that the *Net Present Value* of the SOI organisation is **€4,507,233,** indicating that substantial value is gained from the current operations.

Given the research conducted, SOPHIE provides provisional costs-to-benefit ratios of SOI but the value of the S*pecial Olympics Program* may be significantly broader than can be ascertained in just one study. Integral to the sustainability of the *Special Olympics Program* will be allocating a proportion of available budget (nationally or globally) to co-ordinate a program of research where *value* is central to support future investment.

Specifically, **future research** should consider the value of:

- Event volunteers who have contributed to programmes
- Contribution of the SOI Games (hosted every 4 years)
- Participating in a World Summer Games and World Winter Games (held every 4 years)
- Hosting regional and area games as well as leagues throughout a 4-year cycle
- Participation in support programmes such as Health Promotion and Athlete Leadership
- Media exposure as calculated by a media monitoring organization

Furthermore, it is recommended that the number of volunteers working in community-based-clubs is captured routinely to ascertain and monitor with greater certainty community activity.

9. Overall Discussion

This study demonstrates the feasibility of conducting detailed health surveys and physical measurements in a population with ID. All interviews were conducted face-to-face and one-to-one with a researcher devoted to collecting data from each family unit over a period which typically took from 60-90 minutes. Most of the interviews were conducted in the evening times or at weekends as the participants or their principal family carers were not available during day time hours or week-days. The methodology was resource intensive in terms of research personnel time required but the trade-off was that very detailed objective and subjective data in comparative populations who take part and do not take part in SO programmes was collected, providing unique information on health and well-being in an ID population. In all cases the researchers endeavoured to collect data directly from the person with the ID as this was what the tender document had stipulated was preferable. However, in the majority of cases, the principal participant was supported in answering questions by their principal family carer.

The participants with ID were asked to complete the 2-page ED-5D-3L form themselves without support from their principal family carer, but were supported by the researcher. Participants appeared to have no difficulty in answering the questions on page one of the instrument (which explored Mobility, Self-Care, Usual Activities, Pain/Discomfort and Anxiety/Depression) but they seemed to have a little more difficulty in interpreting the "health thermometer" question on page two. The sample of people with ID who take part in SOI programmes reported a higher health status than those who do not take part in SOI programmes. Self-rated health and quality of life measures are increasingly being recognized as a valid indicator of a person's health status. Studies show that self-rated, health-related quality of life consistently predicts adverse health outcomes.

All of the physical measurements were collected directly from participants by trained researchers. The participants appeared to have no difficulty in having their anthropometric measurements taken and some expressed an interest in getting a copy of their data in a printed format. An individual report containing results of all physical measurements was given to each participant in the format of a "certificate of attendance". There was good compliance with the wearing of accelerometers over the 7-day period, and most of the participants completed the 6-minute walking test without difficulties. No adverse events or accidents occurred during physical data collection time. Family members cheered on their loved ones.

The majority of participants took a 4-day food diary home to keep a record of all foods and beverages consumed for 2 weekdays and 2 weekend days. We suspect a significant level of under-reporting in the food diaries as total intakes from calories do not correlate with BMI levels. Underreporting is not unusual though and is a common methodological issue in ascertaining nutritional intakes in most population, not limited to an ID population (McCrory, Hajduk and Roberts 2002).

No correlation was found between SOI involvement and body mass index or waist circumference measurement. Obesity was a feature of both the SOI and non-SOI group, and was more prevalent than it is in the general population in Ireland but was similar to previous reports in the ID population over 40 years of age in Ireland (McCarron et al. 2014).

Those who took part seemed to enjoy the experience and availed of the opportunity to converse with the ID nurses who were present at data collection. It was clear that many of the families we attempted to recruit were under strain, as they said that they were just too busy to take part. The families who did take part were very generous with their time as many had to travel long distances to and from the centres.

9.1 Main Results

9.1.1 Participants

We invited 1,840 participant groups (athletes or non-athletes and their principal family carers) to take part in the research study. A maximum of four contact attempts by telephone were made to each participant group in order to recruit them. Approximately 8,200 phone calls were made in total in attempting to contact potential participants and subsequently in making arrangements to set up the research interview. Two hundred and ninety-two participants took part in this research; this included 146 primary participants (101 athletes and 45 non-athletes) with an ID and 146 of their principal family carers. 58.2% of the recruited primary participants (athletes and non-athletes) 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 had a mild ID, 46.1% were considered moderate, and 6.4% had a severe ID.

Most of the principal family carers recruited (70%) were female, and most (76%) were parents. Other carers included 27 siblings, and 4 others, 1 niece, and 3 sisters-in-law. The mean number of hours of caring per week was 57, with a median of 28. No differences were detected between measures of quality of life and health status or health services use between carers of athletes and non-athletes.

9.1.2 Health related Quality of Life

People in SOI rate their own health as better than those not in SOI and this was statistically significant ($p = 0.03$). Their principal family carer also reported a difference between the two groups in the proxy reports they completed about health related quality of life, which also was statistically significant. Non-athletes reported higher rates of depression ($p=0.07$ Fisher's exact test) and epilepsy ($p= 0.04$ Fisher's exact test) than SOI athletes. No differences were recorded in individual illness frequency between carers of athletes and non-athletes.

9.1.3 Physical Activity

SOI athletes self-reported significantly ($p = 0.002$) higher mean minutes of moderate to vigorous physical activity (MVPA) daily (28.8± 32) than non-SOI athletes (9.7± 22). A significantly ($p < 0.000$) greater distance was walked in the Six Minute Walk test by SOI athletes (541± 103) compared to non-SOI athletes (436± 100.6). A Health Profile Score was calculated by combining scores from Body Mass Index, Blood Pressure, meeting $\geq$ 30 mins MVPA daily, and distance walked in the submaximal fitness test. This demonstrated that SOI participants scored a significantly ($p = 0.013$) higher overall health profile (2.18 ± 0.81) than non-SOI athletes (1.64 ± 0.70).

9.1.4 Nutrition

Seventy-five percent of the sample was overweight or obese but there was no statistical difference between athletes and non-athletes in terms of Body Mass Index with mean BMI of 29.4kg/m^2 in athletes and mean BMI of 29.4kg/m^2 in non-athletes. The mean waist circumference of SOI athletes was 94.9cm in men and 87.1cm in women. The mean waist circumference in non-athletes was 98.2cm in men and 94.4cm in women. However, the differences were not statistically different between those in SOI and not in SOI. The data highlights poor diet quality in this sample of people with ID, as very few study participants were meeting their micronutrient Recommended Daily Amounts (RDAs). Energy contributed from fat, saturated fat and sugar was greater than recommended in the majority of study participants.

9.1.5 Focus groups with participants, family members and care staff

The focus groups show that SO impacts positively on athletes and their families. The benefits of participation for athletes were wide ranging and included physical and psychological well-being, increased levels of independence, improved social inclusion, and higher levels of self-determination. For families, the benefits included an increased social network and an increased sense of family pride. Families noted the considerable time commitment of being part of SO but acknowledged that the benefits of participation outweighed any potential negatives.

Barriers to participation were identified, with particular difficulties relating to transport, volunteer shortages and demands on older parents articulated. For those not involved in SO it was identified that more accessible information may be an important factor in enhancing the numbers taking up programmes. The current “selection process” (the way in which athletes progress through the 4 year cycle to world games) was identified by almost all athletes and families as a source of dissatisfaction and discontent. It was apparent that staff at the care services involved played an important role in supporting athletes to be able to take part in SO.

9.1.6 Focus groups with Special Olympic Management

SOI staff identified themselves as a “National Governing Body (NGB) for Sport” who provide sporting opportunities for people with ID. Access and financial constraints were identified as barriers to participation in SOI, in a previous report. In this focus group SOI staff reported, however, that they do not believe these barriers fall within their remit to address. This appears to be at odds with the athlete’s views, who reported that they believe SOI should address these barriers.

9.1.7 Economic analysis

SOI programmes support in the region of 380 SOI clubs and 9,000 registered athletes throughout the island of Ireland. Approximately 25,000 volunteers are registered with SOI, of which about 8,000 are active annually. Our analysis shows that SOI operations cost on average €6.04 million per annum over the past 4-year cycle. The value of the athlete training provided by SOI is €7.59 million per annum (95% CI: €4.62m to €10.60m). The value of volunteers to SOI is €1.58 million per annum (95% CI: € 1.23m to € 1.94m). Funds raised in community clubs is an estimated €1,374,516. *Net Present Value* (i.e. expenditure + monetary value of benefits) is €4,507,233. It should be noted that the estimates are conservative, as they do not include the service provider clubs.

9.2 Discussion

This sample of people with intellectual disabilities who take part in SOI programmes have a higher self-reported health status than those who do not take part in SOI programmes. Self-rated health and quality of life measures are increasingly being recognised as a valid indicator of a person’s health status. Studies show that self-rated, health-related quality of life consistently predicts adverse health outcomes. The study also shows that those in SOI have higher levels of physical activity (PA), are physically fitter and have a higher health profile score. Obesity was a feature of both the SOI and non-SOI group, and was more prevalent than it is in the general population in Ireland.

For families of those involved in SOI there appear to be beneficial effects also; these include increased social engagement with other families and enhanced family pride. The barriers to participation in SOI programmes could potentially be overcome with local planning, enhanced communication and re-allocation of funds to tackle transport shortages, and strategic identification of those most in need of this resource at local club level. It is difficult to estimate the net gain from the health and other benefits accrued as a result of SO participation but this study shows that they may exist and can be demonstrated quantitatively and qualitatively.

It must be acknowledged that the team encountered significant difficulties in recruiting participants to the study, particularly from the non-athlete group. This has been recognised as a difficulty in previous studies with persons with ID (Lennox et al, 2005) and is therefore not unique to this study but it does limit the generalisability of the findings. Athletes were relatively easier to recruit than non-athletes and perhaps this is due to the fact that they identified with the research because it was about SO and they felt that it related to them, whereas non-athletes felt it did not, even though the study team went to great lengths to explain that their input was also very valuable to the study. Reasons for low uptake included competing priorities, unavailability, inability to make contact, insufficient verbal communication skills, respite stay, illness, no-show at research interview, transport issues and geographical distance from the pre-arranged sports venue.

9.3 Conclusion

This study provides unique data which has not previously been probed showing the benefits and economic value generated attributable to the work of a voluntary organisation (SOI). Our study provides novel quantitative and qualitative information, giving us a better understanding of the benefits, impacts and experiences of taking part in SOI programmes for athletes and their family carers. It also provides us with useful insights into non-involvement by families of individuals with intellectual disability, which can be used to inform strategies to improve participation rates. The results will be valuable to athletes, their families and to the SO organisation. The Irish state should continue to invest in the health and well-being of people with ID through SO.

It is clear that SOI are fulfilling their mission to "*to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with an intellectual disability, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendships with their families, other Special Olympics athletes and the community*." The good-will of volunteers allows the wide ranging activities to run at a fraction of the cost of what it would otherwise cost the exchequer. In this study we have demonstrated the feasibility of conducting research study in individuals and families living with intellectual disabilities.

9.4 Limitations and strengths

Due to the poor response rates this study cannot be considered a representative study of persons in SO. However, the strengths of the study include a detailed face-to-face survey, physical measurements and qualitative information gathered directly from persons with intellectual disabilities supported by their principal family carers and provides a comparison between a comparable group of people with ID who do and do not take part in SOI. This is the first study of its kind to our knowledge.

9.5 Recommendations

- We recommend that funders/policy-makers ensure that sufficient funds are provided to SOI annually to allow continued support of SOI clubs nationally.

- Future research should be undertaken with sufficient statistical power to detect health gains over multiple time points as a result of SO participation (notwithstanding the difficulties encountered in recruitment).

- Those attending SOI programmes should be supported to continue attending programmes and those not in SOI should be invited, encouraged and supported to attend where possible.

- Efforts to reducing barriers to participation in SOI programmes should be undertaken specifically to address difficulties of transport, costs associated with being involved, increasing volunteer numbers, identifying and addressing issues of particular concern to older parents.

- There needs to be an acknowledgement that current methods of communicating information are not always effective and SO should consider identifying additional ways of promoting participation.

- The selection process with SO needs to be considered by the organisation as there is a general dissatisfaction with the current way in which athletes are chosen for competitions. This may involve a different communication strategy as well as a review of the current system.

- It is recommended that SOI clubs record information on athlete training and feedback this data back to the central SOI organisation to generate national level data.

- It is recommended that SOI clubs record information on all volunteer time provided and feedback this data back to the central SOI organisation to generate national level data.

- In addition, SOI should capture the professional qualifications of volunteers so that a true value of the work they do can be more precisely estimated.

- Healthcare professionals working with people with ID should be made aware of the issue of overweight and obesity in this population and evidence-based interventions for dealing with it.

- Healthcare professionals working with people with ID should be made aware of the reported benefits of participation in SOI emerging from the SOPHIE study and should be encouraged to facilitate as much participation of people with ID in their care in its programmes as possible.

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